Relationships and Growth in Families of Children with Developmental Disabilities: New Ways of Intervening.

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A thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology

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Table of Contents

Chapter Two: Empirical Paper

Chapter Three: Reflective Paper

Engaging in research with families of children on the autism spectrum: Reflections on the impact of individual differences

List of Tables

List of Abbreviations

ANOVA	Analysis of Variance
ASD	Autism Spectrum Disorder
BPS	British Psychological Society
CAMHS	Child and Adolescent Mental Health Services
DS	Down Syndrome
F-COPES	Family Crisis Oriented Personal Evaluation Scales
FSS	Family Support Scale
ID	Intellectual Disabilities
IPA	Interpretative Phenomenological Analysis
KIPP	Kansas Inventory of Positive Perceptions
NHS	National Health Service
Ppt	Participant

List of Appendices

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Declaration

This thesis was conducted under the academic and clinical supervision of Dr. Fiona MacCallum and Ms. Jacky Knibbs. Participants were recruited from Coventry and Warwickshire NHS Partnership Trust. Aside from the collaboration of the above listed supervisors, this thesis is my own work.

This thesis has not been submitted for a degree at another university. The authorship of the papers from the study will be shared with the above named individuals.

Summary

This research examined relationships and positive growth in families of children who have a developmental disability. Chapter one is a critical review of the literature relating to positive growth in parents of children who have a developmental disability. Past studies have indicated that having a child with a developmental disability can be both stressful for parents and place increased pressures on their time, energy and resources. However, this review of more recent research about the experience of having a child with a developmental disability highlights the range of positive growth experiences parents undergo and some of the possible processes involved. Positive growth experiences reported included changes in parental perceptions of their growth, changes in belief systems, increased sense of coherence and increased hope. Resilience, reframing coping strategies, meaning-making and social support were all implicated in this positive growth process. Clinically, the value of strengths-based services for families emerged. Chapter two is an empirical study, focusing on the maternal experience of a family based Lego Therapy intervention amongst five families who have a child who is on the autism spectrum. Qualitative analysis of interview data resulted in themes of family-specific factors (communication, new perspectives, deeper relationships), child-specific factors (impact of the child's ASD, child-specific developments) and intervention-specific factors (ambivalence about the intervention, time). Methodological and clinical implications are discussed, alongside recommendations for future research. Chapter three is a reflective paper focusing on the individual differences to emerge amongst families and the clinical and methodological implications of this.

Chapter One

Factors associated with positive growth in parents of children with developmental disabilities: Clinical Implications

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Paper prepared for submission to Journal of Applied Research in Intellectual Disabilities (see Appendix A for submission guidelines)

Abstract

Background: This paper aims to review the literature exploring positive growth in parents of children with developmental disabilities and to consider the clinical implications of the findings.

Method: A systematic review identified 17 papers.

Results: Changes in parental perceptions of their growth, changes in belief systems including religious belief systems, increased sense of coherence and increased hope were reported as positive growth experiences. Processes implicated in this growth were around resilience, reframing coping strategies, meaning-making and social support.

Conclusions: Findings present clinical implications for more strengths-based service provision. Future research needs to consider under-researched populations. More quantitative research is warranted, though concepts need further definition in order to be measured accurately. Longitudinal research and research investigating the impact of growth on other family processes would be beneficial.

1.1 Introduction

Studies exploring the impact of having a child with a developmental disability on parents have yielded mixed results. Parents of children with developmental disabilities are vulnerable to experiencing higher stress levels (e.g. Most, Fidler, Laforde-Both & Kelly, 2006; Plant & Sanders, 2007; Smith, Oliver & Innocenti, 2001); increased demands on time, energy and resources (Lam & MacKenzie, 2002); and carry a higher risk of physical and mental health difficulties (Dykens, 2000; Emerson, 2003; Hedov, Anneren & Wikiblad, 2002).

However, Scorgie and Sobsey (2000) argued that suggesting having a child with a disability is a wholly negative experience is a pessimistic and biased viewpoint. Summers et al. (2007) reported that 65% of mothers of children with an intellectual disability rate their quality of life as moderate to excellent. Previously, Summers, Behr and Turnbull (1988) found that parents of children with developmental disabilities described their experience as one of growth; learning humility, patience and compassion for others.

Research around stress-related growth as the result of a challenging life experience has developed considerably (e.g. Linley & Joseph, 2004; Walsh, 2006) and is now being applied to families of children with developmental disabilities.

Hastings and Taunt (2002) conducted a review of positive perceptions in families of children with developmental disabilities. Fourteen themes around positive experience emerged from the qualitative research. Quantitative research focused more on lower stress or increased hardiness as compared to directly positive experiences and no clear pattern of which variables were correlated under which circumstances. This suggests that parents of children with developmental disabilities do share some positive experiences, but to what extent this constitutes growth experiences specifically remains unclear. Moreover, though a list of positive experiences was generated from the review, there is little exploration of how these experiences occurred and in what context.

The Hastings and Taunt (2002) review is relevant to the current review in terms of broad topic area but there is little overlap with the current review in terms of papers reviewed and conceptual focus. The current review will consider only parents of children with developmental disabilities rather than parents of adult children with developmental disabilities. Similarly, only parental experiences, rather than family or sibling experiences will be reviewed. The current review will also focus solely on positive growth, rather than positive experiences more broadly. Finally, the current review seeks to explicitly consider the clinical implications of the research conducted since 2000, including the most recent nine years which fall outside of the limits of Hastings and Taunt's (2002) review.

With this in mind, the current review seeks to answer the following questions:

1. What are the factors involved in positive growth in parents of children with developmental disabilities?

2. What are the clinical implications?

A range of terms and definitions have been used within the positive growth literature, resulting in a lack of conceptual clarity. For the purposes of the current review, positive growth refers to any kind of change which parents experience as positive and perceive to be a consequence of having a child with a developmental disability.

1.2 Method

A systematic review of the published literature between January 2000 and February 2011 was undertaken using PsychINFO, MEDLINE, ASSIA, Web of Science and PsychARTICLES. Searches were carried out between September 2010 and February 2011. Table 1. shows the search term combinations employed.

Search Term One		Search Term Two
Autis* *or* Asperger* *or* learning disabilit* *or* mental retardation *or* developmental disabilit* *or* Down Syndrome *or* intellectual disabilit*	*AND*	resilien* *or* religio* *or* spiritual* *or* post-traumatic growth *or* family coping *or* parent* coping *or* maternal coping *or* paternal coping *or* family adjustment *or* parent* adjustment *or* maternal adjustment *or* paternal adjustment *or* hardiness *or* family adapt* *or* parent* adapt* *or* maternal adapt* *or* paternal adapt* *or* family belief* *or* parent belief* *or* maternal belief* *or* paternal belief* *or* sense of coherence *or* family transformation *or* parent* transformation *or* meaning-making *or* stress-related growth

Table 1. Search terms and combinations used to identify literature for review.

Reference lists and citation searches were used to identify additional papers. Exclusion criteria were set to remove non-peer reviewed papers, case studies, non-English language papers and articles published prior to 2000. Papers relating to parents of adult children with disabilities, to children with physical rather than developmental disabilities, to sibling or child-specific experiences, to personal growth non-specific to the experience of parenting a child with developmental disabilities, and to coping with stress rather than specific growth were also excluded. A total of 1791 papers were identified, 1774 of which were excluded. See Table

2 for details of excluded papers. A total of 17 papers were thus identified for inclusion (summarised in Appendix B). Although all papers came from peer-reviewed journals, this is an emergent area and the small amount of research within it meant that no further quality checks were applied.

Exclusion Criteria	Number of papers excluded
Non-peer reviewed	921
Coping with stress (rather than stress-related growth)	189
Children with physical disabilities	163
Parents of adult children	154
Personal growth non-specific to parenting a child with a developmental disability	145
Sibling experiences	123
Child specific experiences	58
Non-English Language	14
Case studies	7
Total	1774

Table 2. Quantity of papers excluded according to each exclusion criteria

1.3 Results

1.3.1 Growth Experiences

1.3.1.1 Parental perceptions of positive growth factors.

Taunt and Hastings (2002) interviewed 14 parents (4 fathers, 10 mothers) of children with developmental disabilities aged 3-18 years, to explore their perceptions of the positive family impact of their child. Thirty-three parents (23 mothers, 10 fathers, including 1 foster parent and 1 adoptive parent) of children aged 1-24 years completed an electronic survey based on the main interview schedule. Content analysis revealed themes of positive growth including having a changed perspective on life, increased support from other families, increased opportunities to learn, improved

family dynamics, increased sensitivity, increased social networks, increased confidence and assertiveness, and strengthened religious faith.

However, participants in the first sample were known to the researcher, meaning they may already have considered the positive impact of having a child with a developmental disability. The second sample required internet access to participate. People who use the internet may be more likely to have a higher socio-economic status and better literacy. Despite this, similar themes were found across the two groups, suggesting some consistency in the parental experiences.

Myers, Mackintosh and Goin-Kochel (2009) examined the experience of parents of children with autism (aged 2-21 years), using a web-based open-ended question, "how has your child in the autism spectrum affected your life and your family's life?". Four hundred and ninety three parents (92.2% mothers, 7.8% fathers) participated. Twenty-four themes were identified using content analysis. Seven of these themes relate to parents' experience of positive growth; having a new understanding of the world of disabilities, feeling their lives are enriched, experiencing increased compassion, tolerance, patience and joy, learning to appreciate the little things in life, having a more fulfilling spiritual life and better marital and family relationships. Given that some negative themes also emerged alongside these growth experiences, Myers et al. (2009) suggested a dialectical viewpoint in which meaning-making is a central tenet of growth in the face of adversity.

Ethnic minorities and lower income families were underrepresented and are groups who may struggle to access support services and could therefore be less likely to experience positive growth. Recruitment through autism organisations means these families might have been more able to seek help initially, supporting their growth prior to participation in the study. Using the internet for data collection precluded prompting participants for richer information.

Scorgie and Sobsey (2000) explored "transformations", defined as significant and positive changes, and categorised these as personal, relational or perspectival. Fifteen parents of children with developmental and physical disabilities were interviewed about their experiences as parents. From the themes identified, a mail survey was developed, with 80 primary caregivers responding. Personal transformations included acquiring new traits such as increased compassion and reduced selfishness, learning they could achieve rather than remain powerless, developing endurance, an increased sense of humour, and gaining the ability to speak out on behalf of their children. Parents discussed having stronger spiritual convictions, usually through strengthened pre-existing beliefs. Relational transformations included stronger relationships with spouses and other children in the family, expanded social networks, increased opportunities to advocate for others, and more tolerance and understanding of the individual differences of other people. Transformations of perspective were seen in changes to parents' view of

life, including changes to their view of life, making the most of each day, a modified view of success, and changed views about what is important in life.

The sample included children with mixed disabilities, though different processes may occur in families of children with different types of disabilities. Only parents who had been identified as "good copers", which was not defined, were included in the study. This is likely to have biased results towards more transformative experiences, though given that such experiences were the focus of the study, this may be a valid selection method. Member checking, in which transcriptions of interviews were mailed to each participant for verification and clarification, was employed to test for reliability of the qualitative data, which adds rigour to the methodology. Unfortunately the qualitative data analysis method is unclear, meaning replication of findings is difficult.

Taking these three studies together, some consistency in reported positive growth experiences can be seen. Changed belief systems or world views in particular are shared across the studies.

1.3.1.2 Belief systems.

King, Zwaigenbaum, King, Baxter, Rosenbaum & Bates (2006) explored the world views, values and priorities of families of children with autism or Down Syndrome and how their beliefs change over time. Nineteen key informants (12 mothers, 3 fathers, 4 service providers) participated in

focus groups. The age of the children was not reported. The data analysis methodology is unclear, though the authors did attempt to demonstrate credibility, dependability and transferability, for example through triangulation and having multiple data analysts.

Emerging themes suggested that raising a child with a disability is a life-changing experience during which families examine their belief systems. Parents gained a sense of coherence and control through changes in their world views, values and priorities. The importance of hope was identified in parents' adaptation process. Changes in world views included having stronger values and broader views; having a greater understanding of themselves; increased patience, acceptance, tolerance, perseverance, compassion and unconditional love; and learning what is important in life. King et al. (2006) argued that these reframing strategies facilitate their adaptation and growth over time.

This study is one of few to include fathers, though analysis does not consider potential gender differences. The indirect, non-biological caring relationship service providers held with the children compared to the biological parents who participated is another difference within participants not considered in the analysis.

King, Barker, Rosenbaum, Zwaigenbaum and Bates (2009) examined family belief systems in parents of children with autism spectrum disorder or Down Syndrome (16 mothers, 10 fathers) using a mixed interview and

questionnaire design. As a result of having a child with a disability, families became more certain of what matters over time, adopting perspectives of optimism, acceptance and appreciation. These perspectives provided families with increased hope, meaning and control, demonstrating their growth in the face of adversity. Participants with children across a broad age range (6-8 years, 15-17 years) were selected, facilitating examination of changes in belief systems of parents over time. Themes of hope, meaning and control were important across all parents. Parents of older children focused more on what they had gained from their experiences, suggesting growth may be an ongoing process which is easier for parents to identify as the child becomes older.

King et al. (2009) highlighted that interviewing two-parent families allows family perspectives to be ascertained through a process of negotiation. They asked service providers to nominate parents who were more or less articulate and more or less successful as a family unit, maximising sample variability. The interview used was based upon the focus groups described in the King et al. (2006) study, and two pilot interviews were used to refine the schedule. The use of two interviews per participant for the core study allowed collection of more in-depth data, giving participants the chance to reflect on the initial interview. Member checking (previously described) was used, to ensure accuracy of transcription and identification of themes. However, children's diagnoses were not confirmed by the researchers, limiting the external validity of findings.

1.3.1.3 Sense of coherence.

Retzlaff (2007) suggested that a family's pre-existing sense of coherence impacts on the extent to which changes in world view and perspectives are incorporated into their narratives around their adaptation to having a child with a disability. Family sense of coherence was defined as a basic motivational and cognitive attitude that regulates families' coping efforts and adaption to stressful life situations, such that a high sense of coherence would mean having confidence that events are predictable, resources are available to meet challenges, and that it is worthwhile and meaningful to make the effort to meet the challenges (Antonovsky, 1987). Six families of girls with Rett Syndrome were interviewed; three with high coherence and three with low coherence. It is not clear which family members were interviewed.

Grounded Theory and Narrative Analysis were used to analyse interview data. All families identified social support and changes in family world view as key to good adaptation. Changes in meaning and world view, including appreciating small things in life and reflecting on life beyond achievements, were more heavily emphasised in families with high coherence. Families with low coherence experienced the adaptation to the disability as more difficult with no clear turning point or closure, focusing more on the ongoing stressors and burdens. In these families, changes in family meanings were less important and were achieved only after a long struggle.

This suggests that sense of coherence may be important in a family's potential for positive growth, though it is not clear how each of the different factors interact. These results, combined with those of King et al. (2006) and King et al. (2009), suggest the relationship between a change in belief systems and sense of coherence may not be uni-directional or linear in nature. However, results were positively biased towards two-parent families in contact with parents' networks, who are actively coping. No families told stories of not coping, excluding alternative narratives. The sample was limited to families of children with Rett Syndrome only, restricting the applicability to children with developmental disabilities for the purposes of this review.

1.3.1.4 Religion and spirituality.

A subset of research has investigated religious belief systems and their role in positive growth. Sorensen-Marshall et al. (2003) interviewed 32 Latter Day Saint parents with a child with a developmental and/or physical disability aged 1-18 years. No formal method of qualitative analysis was applied. Parents described their spiritual experience as part of a positive adaptation process, gaining a different perspective to those who had not had the experience of raising a child with a disability. Though this was a continual up-and-down experience, parents experienced an expanded personal faith through having shared family religious beliefs, increased social support from the church community and family unity in church participation. Faith was a transformative process,

growing from a positive reframing of their situation based on religious beliefs. Parents used faith to make sense of their experiences and subsequently endow their child with special value. Unfortunately, the mix of parents of children with a developmental or physical disability means the potentially different adaptation processes were not distinguished.

Tarakeshwar and Pargament (2001) considered the role that religion plays in the coping process of parents with a child with autism aged 4-24 years. Using both quantitative and qualitative methods, 45 parents (95.6% mothers) completed questionnaires and a sub-sample of 21 parents were interviewed. Greater use of "positive religious coping" was associated with greater stress-related growth; including positive changes in social relationships, personal resources and coping skills. More use of "negative religious coping" was associated with increases in depressive affect and anxiety. Religion appeared particularly helpful in offering parents a sense of meaning, and offering parents an informal social support. This suggests that religion may have an important role to play in promoting the positive growth of parents of children with autism, but that the type of coping employed is crucial.

Unfortunately, the authors did not define what constitutes positive versus negative religious coping, so more clarity is required here before firm conclusions can be drawn. The small sample size limited the power of the statistical analyses, and was drawn from a largely Caucasian background, meaning the results may not be applicable to families from

other cultures. The cross-sectional design means it is not clear whether the correlates of each type of coping are long-lasting.

Using both interviews and questionnaires, Skinner, Correa, Skinner and Bailey (2001) examined religious beliefs and practices in 250 parents of Mexican and Puerto Rican origin who had children with developmental disabilities aged six years or less. The majority of participants' faith increased after learning of the child's condition (70% of mothers, 54% of fathers). Faith brought them solace, comfort, strength and hope. Personal religion rather than institutionalised religion was viewed as offering the most support. Mothers whose cultural environment was "more Latino" professed the importance of faith more than those from more Anglo-oriented environments. Findings indicated that religion, as a system of beliefs, provided the majority of parents with a way to understand and make meaning of the child's disability and their relationship to God, and a way of adapting to and growing as a result of the child's disability.

Though this study contributed to the evidence base by considering the religious belief systems of an ethnic minority, the lack of control group means it cannot be assumed that these processes are specific to Latino families. Methodological strengths include the use of Spanish and English interview schedules which were compared to ensure consistency of meaning across interviews, and the use of pictorial aids to facilitate optimal understanding, regardless of literacy levels. In addition, the use of

quantitative and narrative information added breadth and depth to the data collected.

1.3.1.5 Hope.

Hope has also been identified as a positive transformative factor for families, independent of religion. Kausar, Jevne and Sobsey (2003) explored the experience of hope for families of children with significant developmental disabilities. A case study approach with 19 parents of children aged 3-18 years was used. The data were analysed using a constant comparative method of coding and categorisation (Glaser & Strauss, 1967), though the exact process is unclear.

The experience of having a child with a disability changed over time, from being frustrating and shocking, moving towards an experience of developing emotional strength, meaning in life and personal growth. A number of themes associated with the development and maintenance of a hopeful attitude were identified. Those particularly relevant to personal growth were an increased sense of care and compassion and experiencing positive personal transformations such as enhanced personal resources, increased tolerance and emotional stability, increased family cohesion, the use of spirituality to make sense of their experiences and using social support to share common experiences. The majority of participants reported that parenting a child with a disability became a positive and strengthening experience for them and that hope was strengthened by both their internal and external resources, as

described above. Kausar et al. (2003) concluded that that hope and positive transformation are meaningfully interconnected in the lives of parents of children with developmental disabilities.

Given the qualitative approach employed, causality cannot be implied. The case study approach also limits the extent to which findings can be generalised. However, the authors attempted to increase participant diversity by conducting both face to face and internet interviews, the case study design was well suited to the exploratory nature of the study and inter-rater reliability was established during analysis.

Corman (2009) interviewed nine mothers of children with autism aged 8-18 years about their positive care-giving experiences. Interviews were analysed based on an approach offered by Moustakas (1994) which focuses on the essence of an experience as understood by the participant. All mothers discussed the personal transformation they experienced as a result of their care-giving experiences, focusing on their personal growth in terms of becoming stronger, more empathetic, becoming an advocate for the family and realising what it is important in life. Positive experiences gave families hope in times of difficulty, though it is not clear how this may have led to further positive experiences and growth.

Unfortunately the themes have not been drawn together to provide more detail about these transformative experiences, and so any conclusions

about the specific factors associated with positive growth are limited. The sample differs from the majority of other studies in the field because it is biased towards mothers whose experiences were so stressful that their child was ultimately placed outside the home. Though this still has implications for the generalisability of the findings, Corman (2009) assumed that if this population experienced some positives, then it is likely that less stressed mothers may also have similar positive experiences.

Lloyd and Hastings (2009) explored the role of hope in the psychological well-being of parents of children with intellectual disabilities aged 3-18 years (138 mothers, 58 fathers). Through analysis of the parent-report questionnaires, they found that hope "agency" (the extent to which a person perceives that they can initiate and maintain the actions needed to meet their goals) was found to be a resilience factor in both mothers and fathers' psychological well-being. Hope "pathways" (the person's perception that he or she has the ability to generate workable routes to reach these goals) was only found to be a resilience factor for maternal depression. Lloyd and Hastings (2009) concluded that hope functions in a compensatory way for this population; decreasing distress, and most importantly for this review, increasing well-being.

This is one of few studies to consider how experiences differ between mothers and fathers. Lloyd and Hastings (2002) suggested differences found may be linked to caregiver status rather than gender, because only

four of the fathers participating in the study were the primary caregivers. Measuring hope as a trait can be questioned, given it can also be measured as a state, amenable to change over time. This is particularly relevant when considering how hope interacts with positive growth experiences longitudinally. Lloyd and Hastings (2002) pointed out that the Trait Hope Scale may not be psychometrically sound because all items are scored as positive items and may encourage respondents to respond positively when completing the scale.

Despite these limitations, Kausar et al. (2001), Corman (2009) and Lloyd and Hastings (2009) all support increased hope as a potential positive growth experience of parents of children with developmental disabilities. The findings suggest that a number of possible factors may contribute to increased hope, and that this increased hope can act to facilitate higher parental well-being.

1.3.2 Processes of Positive Growth

1.3.2.1 Resilience.

Bayat (2007) argued that parents can become resilient as a result of having a child with autism. Walsh's (2003) definition of resilience was employed, in which resilience is defined as not only the ability to withstand hardship and rebound from adversity, but also the process of becoming strengthened and more resourceful. Walsh (2003) defined three key factors which contribute to a family becoming resilient; making

meaning of adversity, affirming strength and keeping a positive outlook, and having spirituality and a belief system.

A survey methodology of 167 parents and other biological primary caregivers of children with autism aged 2-18 years was employed to gather qualitative data in response to open ended questions. Using Walsh's (2003) model as a basis for the thematic analysis, several processes involved in developing resilience were identified. Families discussed becoming more connected as a family, gaining spiritual strength, becoming more compassionate and adopting a changed world view. They reported a greater appreciation of life and other people and having learnt some lessons about the meaning and purpose of life. Adopting a changed world view as a process to facilitate growth is supported by King et al. (2006).

A further eleven categories with a positive orientation were identified, but because they did not fit into Walsh's (2003) definition of resilience, they were not reported. These categories may reveal further information about the positive growth parents of children with autism experience. It is not stated whether Walsh's (2003) model has been validated or what research it is based on, and thus it could be questioned to what extent it is valid to report results which fit solely within this model. Though Bayat (2007) described the factors above as contributing to a family's resilience, the lack of clarity about what promotes these processes in some families rather than others, and to what extent pre-existing baseline resilience

may contribute to the ability to engage in these resilience-enhancing processes is acknowledged.

This study had a large sample, albeit not randomly selected and with a bias towards white upper-middle class families. Bayat (2007) reported that answers to questions were relatively short and it is possible that a smaller sample responding to more in depth questions could have yielded richer data. Prompting participants is not possible within a survey study and so Bayat (2007) suggested exercising caution when generalising these results. Bayat (2007) also pointed out the lack of opportunity within this study for triangulation and multiple checks, which reduces the validity of the conclusions drawn.

The factors Bayat (2007) identified as contributing to developing resilience, in itself a positive growth experience, have also been identified by Myers et al. (2009) and Hastings and Taunt (2002) as positive growth experiences in their own right. This suggests that the experience of growth may be a layered and interactive experience in which different growth experiences impact on and contribute to the development of each other.

1.3.2.2 Reframing coping strategies.

Hastings, Allen, McDermott and Still (2002) explored factors related to positive experiences in mothers of children with intellectual disabilities aged 4-19 years. Thirty-nine biological mothers and two foster mothers

completed self report questionnaires. Regression analyses revealed that mothers' perceptions of the child as a source of personal growth and maturity were positively associated with reframing coping strategies, the helpfulness and usefulness of support from family and friends and care-giving demand. Hastings et al. (2002) suggested this latter finding may be a result of mothers rising to the increased challenges of a higher care-giving demand and so enhancing their feelings of efficacy which contribute to personal growth and maturity. This use of reframing as a facilitator to adaptation and transformation was also found in King et al.'s (2006) study.

The low response rate means the sample is unlikely to be representative of all parents of children with intellectual disabilities. Fathers were excluded from the study due to the mother-father differences that have been reported in the family research on disability, yet foster mother responses were still included, despite research highlighting the different obstacles foster parents may experience compared to biological parents (e.g. Howe, 2005; Howe, 2006; Howe & Fearnley, 2003). Hastings et al. (2002) found little overlap in item content between the measures, strengthening the study's validity. The Kansas Inventory of Positive Perceptions (KIPP; Behr, Murphy & Summers, 1992), employed to measure perceptions of the child as a source of personal growth and maturity and as a source of strength and family closeness, has reportedly good psychometric properties.

1.3.2.3 Meaning-making.

Hastings and Taunt (2002) reviewed the published research investigating positive perceptions in families of children with developmental disabilities. Despite different samples, methodologies and ways of conceptualising positive perceptions and experiences, there was still a good level of agreement across qualitative studies in terms of key themes. Parental perceptions which related to growth specifically included perceiving the child as providing opportunities for them to learn and develop, strengthen family relationships or marriage, develop a new or increased sense of purpose in life as well as new skills or career opportunities, become a better person (e.g. increased compassion and tolerance, being less selfish), increase personal strength and confidence, expand social and community networks, increase spirituality, adopt a changed life perspective and make the most of each day more.

In the quantitative research reviewed, Hastings and Taunt (2002) highlight that different variables are associated with positive and negative perceptions, and that these relationships may be moderated by family member variables such as parent gender. However, it remained unclear exactly which experiences and perceptions are associated with which psychological and demographic variables and under what circumstances.

Of particular interest is the discussion of Scorgie, Wilgosh and McDonald's (1999) qualitative analysis of the mechanisms involved in parental positive transformations. Parents experienced a transformation

through the need to form a new identity, attempting to derive meaning from the situation and developing a sense of personal control. This meaning-making echoes Bayat's (2007) suggestion that finding meaning out of adversity is important in a family's ability to become resilient, whilst the development of a sense of control links to the Retzlaff (2007), King et al. (2006) and King et al. (2009) studies of positive change.

Unfortunately, Hasting and Taunt's (2002) reviewing method is unclear, in particular regarding how the papers for inclusion were selected or where they were identified. This review included studies of families with adult children with developmental disabilities, in which the processes of positive growth may be quite different to that experienced by parents of younger children.

Scorgie, Wilgosh and Sobsey (2004) developed a theoretical model of the process of transformation in parents of children with disabilities. Using the existing literature and a case study methodology to support their conclusions, they suggested that three overlapping processes of image making, (constructing new images of what life and their child will be like), meaning-making (making sense of what has happened and why) and choice making (deciding how to live in light of the child's disability) occur which facilitate parents' transformative experiences. This is one of few attempts to develop a theoretical model of transformation with this population. However, it drew on a broad range of literature, including adult physical health, and so might not reflect aspects of transformation

which may be associated with parenting a child with disabilities specifically. The model has currently yet to be tested beyond the case studies presented, limiting its validity.

1.3.2.4 Social support.

Greer, Grey and McClean (2006) aimed to explore the relationship between parental coping strategies and levels of positive perceptions amongst 36 mothers of children with an intellectual disability 5-8 years. Participants completed self-report questionnaires about child behavioural and emotional difficulties, levels of care demand, family supports, coping, and positive perceptions. Hastings and Taunt's (2002) model of families' perceptions, in which positive perceptions function as coping strategies for families, was used to guide exploration of the relationships between these variables.

Quantitative data analysis showed that participants agreed with statements that their child was a source of family strength and closeness (75% of respondents) and a source of personal growth and maturity (58%). These factors were measured using the Kansas Inventory of Positive Perceptions (KIPP, Behr et al., 1992), as in Hastings et al.'s (2002) study, and thus the same critique applies. Perceived helpfulness of formal social support significantly predicted mobilising the family to acquire and accept community help. This in turn predicted levels of family strength and closeness. Though Greer et al. (2006) did not draw the link explicitly, Bayat (2007) suggested that family strength and closeness is

required to promote the development of resilience, another positive growth factor.

Perceived levels of social support and cognitive coping strategies were not associated with closeness or personal growth in these families. This contrasts with Hastings et al. (2002) finding that parental positive perceptions were associated with positive reframing and using social support as a coping strategy. It is possible that Hastings et al.'s (2002) hypothesis would have been supported in a sample reporting higher use of reframing and social support. However, Greer et al. (2006) argued that the amount of variance accounted for by perceived levels of social support and cognitive coping strategies was relatively low and suggested Hastings et al.'s (2002) model thus has reduced explanatory power.

Greer et al.'s (2006) sample was broader than other studies because it included biological, adoptive and step-mothers. Whilst this can be seen as a potential strength in terms of generalisability, grouping these participants together may mask differences between them. Mothers who did not speak English or who had literary or cognitive difficulties were excluded, representing a group who may be particularly susceptible to stress, and thus reducing the study's external validity. Results may also not generalise to mothers of children with more severe difficulties, given that the majority of respondents rated their child as within the normal range for behavioural and emotional problems, and "easy" to look after. The small sample size limits the power of the statistics employed.

1.3.3 Clinical Implications

1.3.3.1 Implications for parents: Shared stories.

The studies reviewed suggest that positive perceptions and positive growth should be intervention goals when working with parents. Parent support groups, in which stories can be shared amongst parents at different stages of the transformation and adaptation process, have been proposed (Greer et al. 2006, Hastings et al., 2002, Retzlaff, 2007, Scorgie & Sobsey, 2000, Taunt & Hastings, 2002). Retzlaff (2007) suggested that the opportunity to share narratives with other families may increase family resilience.

King et al. (2006), King et al. (2009), and Scorgie and Sobsey (2000) advocated sharing research findings with parents, to help validate parents' current perspectives and help build a sense of hope from the many life-changing benefits other parents report. They suggested that this full range of possible experiences should also be made clear to prospective parents.

1.3.3.2 Implications for clinicians: Focusing on positive growth.

All studies reviewed argued for the provision of a strengths-based service for parents of children with developmental disabilities, in which positive experiences are acknowledged and built upon. Transformation does not occur in absence of stress and therefore the goal of family intervention need not be the elimination of stress, but instead could be promotion of

positive experiences (Scorgie, Wilgosh and Sobsey, 2004). This may in turn increase families' awareness of their own potential for growth and resilience (Bayat, 2007). Active interviewing, in which the interview acts as a meaning-making process between the interviewer and interviewee, could then help draw attention to positive experiences and facilitate better coping, and thus a better quality of life for the carer and care receiver (Corman, 2009). Parents' meaning-making is identified within this review as a possible positive growth process, supporting this suggestion.

Greer et al. (2006) proposed that assessments of parental perceptions of their positive growth may help monitor changes in parental coping, and thus provide useful indicators of where and when to target interventions. Service professionals need to work with a positive outlook for people with disabilities in order to promote this strengths-based approach; Kausar et al. (2003) found that parents' hope was reduced by negative professional evaluations of their child, suggesting a need for clinicians to increase their positive and hopeful interactions with parents. Hope itself may be amenable to change as a cognitive variable and may be a possible intervention point, providing parents with an alternative way of perceiving set-backs and thus responding in a more positive way (Lloyd & Hastings, 2009). Methods based on Acceptance and Commitment Therapy (Blackledge & Hayes, 2006) were suggested as potentially useful because they can focus more on the "hope agency" rather than the "hope pathways" discussed.

Being sensitive to family belief systems in professional interactions with families, such as by determining the family goals of service contact, may help increase hope (King et al., 2006). Sharing findings with families may open up dialogue around parental beliefs and priorities, which would help build service engagement and thus help provide services that promote resilience. Sorensen-Marshall et al. (2003) argued that considering families' religious beliefs helps them to adapt and grow from their experiences. Professionals need to ensure that families feel safe enough to share such personal perspectives. Parents may need support in expressing ambivalence they may feel towards God, particularly given the negative parental outcomes associated with such "negative religious coping" (Tarakeshwar & Pargament, 2001). For parents who see religion as a positive resource, professionals might consider encouraging religious coping as a way of gaining strength and growth.

The role of sense of coherence in parental growth has also been highlighted. Retzlaff (2007) argued that families with a low sense of coherence may have less opportunity to tell narratives, for example due to having less social support, and so family therapy or interventions in which the small but great moments are acknowledged may support the development of a new family identity.

1.3.3.3 Implications for service providers: Demonstrating outcomes.

King et al. (2006) and King et al. (2009) suggested that considering research around family belief systems and how they change over time can give service providers a framework for understanding what matters to families, which will aid service engagement and effective service delivery. To enable and encourage clinicians to work within this strength-based approach, policies guiding their work need to reflect this (Bayat, 2007). This could include regularly using a measure of positive experiences as an indicator of parental well-being and coping, in order to prevent a crisis rather than intervening only at crisis point (Corman, 2009).

Increases in parental perceptions of positive growth could be used to demonstrate service effectiveness (Greer et al., 2006). However, if positive perceptions are important intervention goals for working with parents, then clinicians require the tools and skills to be able to explicitly measure them (Hastings & Taunt, 2002). This is particularly relevant given the recent publication of the Transparency in Outcomes: A Framework for the NHS (2010). Service providers need to consider how they are perceived by parents and families, given that the perceived helpfulness of formal support has likely implications for accessing community help, which in turn has implications for family closeness and the development of resilience (Greer et al., 2006).

1.4 Discussion

1.4.1 Summary of Findings

A review of the 17 identified papers highlighted that parents of children with developmental disabilities report a range of positive growth experiences, including increased empathy, changes in their belief systems including developing stronger religious faith, improved relationships, an increased sense of role or purpose in life, a higher sense of coherence or control, and increased hope. A number of relevant factors or processes involved in this positive growth were identified, including increased resilience, the use of reframing coping strategies and meaning-making and the use of social support, though the pattern of relationships and processes needs clarification. This review adds to the previous literature, and Hastings and Taunt's (2002) review in particular, by considering findings from recent research and giving considerable space and thought to the clinical implications of these findings, including the potential importance of sharing stories for parents, a strengths-based approach for clinicians, and the option of measuring positive growth as an outcome for service providers.

1.4.2 Methodological Limitations

Alongside the study-specific weaknesses, a number of limitations which spanned the majority of the reviewed studies were identified. There is a lack of consistency in conceptual definitions, both within each paper and across the literature. Within the quantitative studies, these concepts have

been hard to measure, often with different tools used, making comparison of results between studies difficult.

This may explain in part why the large majority of identified studies employed an either entirely or predominantly qualitative method. Whilst this allows rich, detailed data gathering from the perspective of the parent, it lacks applicability to other groups or populations. The reliance across the qualitative and quantitative studies on self-report arguably limits the results; some external measures may have bolstered the validity and reliability of the findings. It also poses a difficulty in ascertaining whether parental perception of growth reflects a more objective growth process or not, though this is arguably unimportant if the parental perception of growth leads to positive outcomes for the family.

Participants were largely mothers, and where fathers were included, any differences between their experiences were not drawn out, meaning little is known still about father experiences specifically, or the gender differences involved in positive growth in this population. Similarly, some of the studies included a minority of non-biological parents and carers, though did not separate out their results according to the type of carer. This may have confounded results if different processes operate in positive growth amongst different carer groups.

None of the studies included drew comparisons with parents who do not have a child with a developmental disability or to parenthood in which

there are other types of challenges such as chronic health problems. This means it cannot be assumed that the experiences and processes identified are exclusive to this population. It may be that many parents, regardless of the disability status of their child, experience positive growth as a consequence of having a child, though whether these experiences and processes are similar or different to those parents who have a child with a developmental disability is currently unknown. Consequently, the overall findings of this review need to be interpreted with this caveat in mind.

1.4.3 Future Research

Though the findings across studies were relatively consistent, the lack of quality control applied to papers may have biased the review findings more broadly. For example, the selective nature of many of the samples may mean findings are not applicable to wider populations. Future reviews could seek to review a smaller number of papers with stricter inclusion criteria, with a view to checking the validity of the current conclusions.

The review findings lead to some further questions. Given that most of the studies focus on middle class Caucasian mothers, more research is required with more diverse and under researched participants, such as ethnic minorities, parents with disabilities, single parents and fathers. This should also include the relevance of different cultures and religious belief systems, which have been highlighted as important in parental growth.

More research regarding the adaptive function of religion and the ways that religion as a belief system may foster more positive interpretations and personal transformations around disability is warranted.

Given the heavy qualitative focus, more use of mixed methodologies could be employed, which would help provide more quantitative information and also acknowledge the current difficulties operationalising the relevant concepts. Research is required to better operationalise these variables and thus allow this quantitative data collection.

Longitudinal research is also required to investigate how changes in positive perceptions of growth change over time and how previous perceptions of growth impact on subsequent growth, which may then impact on service provision aiming to increase these growth experiences.

Little is known about the impact of parental growth on the rest of the family, or how parental growth interacts with other family processes such as attachment and bonding (Scorgie & Sobsey, 2000). More research is required to examine differences in positive growth experiences of carers with differing parenting status. Finally, more research is warranted around the specific processes involved in positive growth in parents of children with developmental disabilities, as a population who may benefit greatly from its promotion.

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Chapter Two

Maternal experience of Lego Therapy in families with children who are on the autism spectrum: What is the impact on family relationships?

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(see Appendix A for submission guidelines)

Abstract

This study aimed to explore mothers' experience of implementing Lego Therapy (LeGoff, 2004) at home within the family. Following a Lego Therapy training session, mothers carried out hourly sessions with their child on the autism spectrum and the child's sibling, once a week, for six weeks. Mothers were interviewed following the intervention, and this data was analysed using Interpretative Phenomenological Analysis (Smith, Flowers & Larkin, 2009). Themes emerged around improved family relationships, a positive impact on the child as an individual, and changed maternal, sibling and child perspectives. Challenging and facilitative aspects also emerged, as did some ambivalence about the impact of the intervention in light of the wider context. The findings are supportive of previous Lego Therapy studies and have implications for strengths-based service provision, aiming to empower families.

2.1 Introduction

2.1.1 The Autism Spectrum and Family Relationships

Children who are on the autism spectrum experience social difficulties which have been widely documented as impacting on their ability to form relationships (e.g. Konging & Magill-Evans, 2001; Orsmond, Krauss & Seltzer, 2004). Diagnostic criteria are found in Appendix C. Kaminsky and Dewey (2002) suggest that the communication and behavioural difficulties often exhibited by children on the autism spectrum can be particularly challenging and disruptive within families.

Wide variability in parent-child and sibling relationships of children with autism has been described in the literature to date. Montes and Halterman (2007) reported that despite increased stress levels, mothers of children on the autism spectrum showed remarkable strength in their parent-child relationships. Orsmond, Seltzer, Greenberg and Krauss (2006) suggested that characteristics of both the child and the mother affected these relationships. Bagenholm and Gillberg (1991) found that siblings of children on the autism spectrum held more negative perceptions of their sibling relationship, compared to siblings of children with other developmental disorders and typically developing children. Kaminsky and Dewey (2001) found that sibling relationships of children on the autism spectrum were characterised by less intimacy, pro-social behaviour or nurturance than the sibling relationships of children who have Down Syndrome or are typically developing, but that siblings also reported greater admiration of their sibling on the autism spectrum and less quarrelling and competition in their

relationships compared to normally developing peers, highlighting the varied nature of sibling relationships in this population.

2.1.2 Family Relationship Interventions

Every Child Matters (2004) states that all children should have the support to develop positive relationships and that carers, parents and families are key to this process. Family systems theory suggests that the family operates as an interactive unit, with each member affecting each other member and so argues that any intervention should support all family members, rather than the child in isolation (Seligman & Darling, 2007). Whilst the role of the family has been considered in intervention studies for children on the autism spectrum (e.g. Jones & Schwartz, 2004; Schertz & Odom, 2007), the impact of interventions on family relationships has yet to be directly examined.

2.1.3 Social Communication Skills Interventions and Lego Therapy

Lego Therapy (LeGoff, 2004) evolved as a consequence of such ongoing attempts to provide effective social skills therapy for children who are on the autism spectrum. The well-recognised impact of the social communication difficulties that children on the autism spectrum experience, on their relationships has resulted in a range of social skills interventions have been employed and favourably reviewed in recent years (e.g. Lopata et al., 2010; Rao, Beidel & Murray, 2008; Reichow & Volkmar, 2010; Sansosti & Powell-Smith, 2006). However, many of these are based upon social learning theory (Matson, Matson & Rivet, 2008) despite these children often having difficulties attending to social learning opportunities and little intrinsic

motivation to learn such skills (Attwood, 1998). LeGoff (2004) suggested that though children may be able to demonstrate social behaviours when prompted by adults, a failure to generalise these skills or initiate social interaction remained. He argued that many social skills interventions for children on the autism spectrum are viewed as difficult, irrelevant and un-engaging, yet his clinical observations suggested a shared interest in Lego. Using Lego in structured and collaborative play capitalises on the child's natural interest and choice of materials, and subsequently improves motivation and engagement (Koegel, 1995).As a consequence, LeGoff (2004) designed Lego Therapy, starting initially with just two children, building up to nine groups of children, varying in age from pre-school to high-school. As the groups developed, so did the need for clear rules, roles and structure.

To date, Lego Therapy has involved placing children with autism into groups of three and asking them to build Lego sets together by following instructions provided, and with a social division of labour. This model requires joint task focus, shared attention, sharing, problem-solving and mutual goals, relying on each other and communicating effectively (LeGoff, Krauss & Levin, 2010). No external rewards are required. Each child takes on one of three roles, rotated at regular intervals:

- Planner – reads the instructions
- Searcher – find the pieces
- Builder – builds the model

Three studies have investigated the use of Lego Therapy within groups of children on the autism spectrum (LeGoff, 2004; LeGoff & Sherman, 2006; Owens, Granader, Humphrey & Baron-Cohen, 2008). Lego Therapy interventions have lasted between 12 weeks and 36 months. Using quantitative measures, all studies found increases in social competence when compared to either pre-treatment or Social Use of Language Programme control groups. Social competence was defined as motivation to initiate social contact with peers, the ability to sustain interaction with peers, and overcoming difficulties such as aloofness and rigidity. These results suggest Lego Therapy can have a positive impact beyond that of some other social skills interventions. All authors additionally note the high engagement levels that children participating in the groups showed, supporting the notion that Lego Therapy is a motivating means for children to improve their social skills. LeGoff and Sherman's (2006) study found improvements in social adaptation and competence in natural settings, beyond the Lego Therapy sessions themselves. These studies were all conducted with unrelated children in clinical settings.

Though the exact theoretical underpinnings of Lego Therapy are not clear at this stage, it may be that Lego acts as a bridge between the two worlds of autism and social competence, allowing an opportunity to develop social skills and relationships in a context which feels more structured and appealing to children with autism. The appeal of systems has been used previously to motivate children to improve their emotion recognition skills

(Golan & Baron-Cohen, 2006), suggesting this method may be applicable to social skills. Attwood (1998) argued that children who are on the autism spectrum lack the desire to please others; ignoring the social pressures to conform to peer groups, imitate peers, cooperate with them or compete with them, and that social skills interventions which rely on peer instruction or peer modelling have little impact. It is possible that Lego Therapy provides an alternative means of motivation, whilst still providing opportunities to build social skills.

2.1.4 Lego Therapy and Families

Schertz and Odom (2007) supported family inclusion and relationship-based approaches in interventions for children on the autism spectrum, arguing that it can facilitate learning and capitalise upon the role of the caregiver as the primary medium for social communicative learning. Though Lego Therapy has yet to be implemented within families, LeGoff (2004) included siblings as helpers, and found they were familiar with the problems of their sibling and required little prompting to provide redirection for stereotyped behaviours or tantrums. In an evaluation of a Lego Therapy group for children on the autism spectrum, Boorman, Kent and Knibbs (2009) found that parental interest in becoming involved in and learning more about Lego Therapy was high.

Given the potentially positive impact of Lego Therapy and the lack of research into family relationship-focused interventions, the current study aims to explore the lived parental experience of implementing Lego Therapy

at home within families, and in particular how Lego Therapy is experienced by parents in the context of their family relationships. In this format, the three Lego Therapy roles will be taken by a parent, child and sibling.

Lego Therapy studies to date have been conducted in clinic settings, and though Lego Therapy skills may be transferable to other settings (LeGoff, 2004), this has not been researched. The impact of confounding variables has not always been avoided; participants in LeGoff's (2004) study also received weekly 1:1 Lego Therapy sessions alongside the group intervention and ratings of children's interactions and behaviours were not blind. Furthermore, in LeGoff and Sherman's (2006) study, findings may have been confounded by a lack of random assignment to treatment groups and different therapists facilitating each group.

The current study will adopt a qualitative approach in which more detailed data about the parental experience of using Lego Therapy in family settings is gathered, in order to seek an alternative, more ecologically valid perspective.

2.1.5 Aims and Research Questions

- What is the lived parental experience of using Lego Therapy within their family at home?
- How do parents experience Lego Therapy in the context of their family relationships?

2.2 Method

2.2.1 Ethics

Ethical approval was obtained from Coventry University Research Registry Unit, the Black Country Research Ethics Committee and Coventry and Warwickshire National Health Service (NHS) Partnership Trust Research & Development Department (see Appendix D). Informed consent was obtained from participants prior to participation, and all information was kept confidential, anonymised and non-identifiable, as per British Psychological Society Code of Ethics and Conduct (BPS, 2009). Participants have been given pseudonyms for the purposes of this paper.

2.2.2 Participants

Fifteen mothers were identified and contacted through a local Child and Adolescent Mental Health Service (CAMHS) using opportunity sampling, seven of whom opted to participate. Participants had to have a minimum of two children aged 5-16 years, at least one of whom was on the autism spectrum. Of the seven participants, two participants were excluded following the intervention phase; one because it was not possible to complete the interview in the timescale required, and one because there was considerable variability in administration with a different parent completing the intervention with the children each week.

Two participants reported that they were between 30-40 years, with the remaining three being 40-50 years. Mean age is not available. Three were married, one was co-habiting and one was divorced. Three were not working,

one worked part-time and one worked full-time. Four of the mothers identified themselves as White British, one identified as White Other.

A total of ten children in five sibling pairs participated; six children with an Autism Spectrum Disorder (ASD) and four children without ASD. Children with ASD had a diagnosis of Autism, Asperger Syndrome or Pervasive Developmental Disorder, verified by the Lead Clinician. In one family, both children were on the autism spectrum.

The target children with ASD (4 boys, 1 girl) were between 8.4 and 11.8 years old (mean age = 10.2 years, S.D. = 1.5 years). Two children were receiving ongoing Psychology services, one child was in contact with Psychiatry services and two children were open to CAMHS but receiving no current ongoing treatment. Two children were on medication (1 x risperidone, 1 x sertraline). Siblings (4 boys, 1 girl) ranged from 6.8 to 12.4 years (mean age = 8.4 years, S.D. = 2.4 years). All children attended mainstream school, except one family who homeschooled their children.

2.2.3 Measures

An individual semi-structured parental interview was designed in collaboration with the Clinical and Academic Supervisors (see Appendix E). The first two interviews acted as pilot interviews in which feedback from participants was gathered about the interview schedule, though no amendments were required. The interview aimed to gather qualitative data

about the parent-child and sibling relationships post-intervention and the experience of implementing Lego Therapy in the family.

2.2.4 Design and Data Analysis

The study used a qualitative interview design. Data were analysed using Interpretative Phenomenological Analysis (IPA) according to Smith, Flowers and Larkin (2009). Full justification for use of this method of analysis and step by step details of the procedure are found in Appendix F. The context of this study as Action Research, in which an innovative and novel approach to working with families of children on the autism spectrum was core to its process, is particularly relevant. Given the focus on the lived experience of parents of delivering an intervention in this way, IPA was a particularly suitable analysis method to employ. Independent audits of the analysis process, in which the researcher's initial notes, emergent themes and superordinate themes are checked for validity, were carried out within the supervisory team and also with an independent Trainee Clinical Psychologist.

2.2.5 Procedure

2.2.5.1 Recruitment.

Possible participants were identified and initially contacted by the Clinical Supervisor in her role as Lead Clinical Psychologist of the CAMHS, who gave them a participant information and opt-in form. This included contact details of the researcher, and both the Clinical and Research Supervisors

(Appendix G). Using this opt-in information, interested participants were then contacted by the researcher.

2.2.5.2 Training sessions.

Participants and the two children were invited to attend a training session at the CAMHS clinic. Written consent and demographic information was gathered from the parent at this point (Appendix H). Further information about Lego Therapy was provided and a trial session facilitated by the researcher was held for each family, lasting up to an hour. Children were given an information sheet and their written assent was sought (Appendix I). Families were given laminated copies of Lego Therapy rules and roles to assist them whilst carrying out the intervention (Appendix J).

2.2.5.3 Lego Therapy sessions.

Participants then held six Lego Therapy sessions, of one hour each, on a weekly basis. Each family used a Lego set and the instructions provided to try to build a Lego model. Each family member (parent, child and sibling) adopted one of the three previously outlined roles, swapping at regular intervals. The researcher telephoned each parent half-way through the intervention phase to provide any ongoing support that was required and to check for treatment fidelity. Parents were also able to telephone the researcher or the Clinical Supervisor if they had any concerns or queries, though none felt the need to take up this opportunity.

2.2.5.4 Parental interviews.

Following the intervention phase, parents were invited to individual interviews, lasting up to one hour, held at the CAMHS clinic. All interviews were recorded using a digital Dictaphone and identifiable information was removed during transcription.

2.2.6 Subjectivity and Reflexivity in the Research Process

Elliott, Fischer and Rennie (1999) discuss the importance of owning one's own perspective in qualitative research, including the researcher being able to recognise the impact of their values, interests and assumptions on the understanding they draw from the data. By describing such perspectives here, readers are encouraged to consider alternative interpretations and understandings.

The researcher in the present study has an interest in family relationships as well as systemic models of therapy, in which strengths as well as difficulties are highlighted. The researcher is not a mother herself, which has implications for her understanding of the experience of a mother-child relationship. In addition, the researcher had worked at the research site in a clinical capacity in the past, and though had not had any contact with the current research participants, may have made assumptions about the care and treatments the families were receiving.

2.3 Results

Four of the five participants included completed the intervention. The participant who was unable to complete the intervention (Diane) was included in the analysis to ensure an even representation of the experiences of families attempting to implement Lego Therapy at home.

Three superordinate themes were identified, with seven subordinate themes, as shown in Table 2. A section of one transcript showing initial notes and emergent themes can be found in Appendix K. All participants were given pseudonyms. Numbers following quotes refer to transcript line numbers.

Superordinate Themes	Subordinate Themes	Emergent Themes
Family-Specific Factors	Communication	• Improved mother-child communication • Improved sibling communication • Improved communication in extended family relationships
	New Perspectives and understanding	• Better understanding in mother-child relationship • New perspectives for children about ways of behaving • Alternative ways of spending time together • Value of family time
	Deeper and more mutual family relationships	• Mutual respect in the mother-child relationship • Mutual acceptance and appreciation in the sibling relationship • Increased joint play and shared interests in sibling relationship • Deeper sibling bond • More mutually positive sibling relationships
Child-Specific Factors	Impact of ASD	• Child's anxiety • Enthusiasm for Lego • Value of rules • Implicit learning
	Child-specific developments	• Decreased aggression • Increased focus/concentration • Increase in abstract thinking • Increased self-esteem • Improved communication • Increased flexibility
Intervention-Specific Factors	Time	• No time • Right versus wrong time
	Intervention ambivalence	• Reality of a home-based, family-based intervention • Intent to continue and hope for future

Table 3. Superordinate, subordinate and emergent themes

2.3.1 Family Specific Factors

All mothers talked about the impact the intervention had on their family relationships, focusing in particular on their relationship with the target child and the sibling relationship. An interactional process seemed important to this, as improved communication, understanding and a different way of sharing time together all impacted on the family relationships.

2.3.1.1 Communication.

Mothers talked about the ways the intervention impacted on their family communication, focusing in particular on their own communication with their child. Lego Therapy was experienced as providing a setting in which mothers were reminded of the need for simple and clear communication:

> It's improved our communication which I think is the, the best bit of it all...it's like a beam of light that's sort of, okay, we've got to rethink this, we've got to calm it down...this has shown me that he does struggle and it's enabled me to simplify my language and that has to be the, the best thing that Lego Therapy has done (Lucy, 495-505).

Improved communication was also a notable outcome for the relationship between siblings, particularly in terms of an increased awareness of what is required for effective and enjoyable communication together:

> It's certainly helped Danny and Chris, they're squabbling less. It sounds pathetic, they're children, they squabble, but it's made them both realise that they have to speak nicely to each other (Lucy, 222-228).

In addition to the impact on the mother-child and sibling communication, the impact of the intervention on other family relationships also emerged for a sub-section of participants. Two mothers talked about the way in which they were able to share their learning with the child's father, helping them to

improve their communication with the child and providing new interaction opportunities for the father-child dyad:

> It's certainly enabled me to sort of say to my husband "look Danny has problems with verbal language, if you speak to him quickly, you might as well just not bother because he won't follow all that you're saying", and that's helped him understand that it's not just him. Because Graham tends to sometimes see Danny and him, himself, being in some sort of long-lasting battle, whereas now I think he can see that it's actually genuinely a problem for Danny, and it has helped him to speak slower and calmer with him, just because I can say "look, it's not you, it is just he can't cope with that speed" (Lucy, 204-218).

The lessons this mother learnt about communication through the Lego Therapy also helped her in her marital relationship:

> It's improved my relationship with my husband, just by making me more aware of the way you speak and how you convey information, and I think that has been, especially with regard to the boys, I think it's, it's put a spotlight on the fact that I'd always assumed that my husband knew what I knew about autism, which in reality, he doesn't, because he just won't get involved with it, but now I accept that and try to explain things more simply (Lucy, 409-419).

This extended impact may have only occurred where the mother was able to share the skills and lessons learnt with the wider family.

2.3.1.2 New perspectives and understanding.

All mothers reflected on the lessons learnt and new perspectives gained through participation in the intervention. Though for the mothers these shifts were related to changes in relationships and changes in the child, a sense of changed perspective emerged as a distinct theme.

The "beam of light" that Lucy refers to experiencing during the Lego Therapy sessions largely refers to the impact on the family communication, but also highlights how it provided a spotlight for the child's difficulties, allowing

mothers to consider more deeply how to best manage these. Mothers felt they had gained a better understanding of their child and that this in turn impacted on the quality of the relationship. An interactional process emerged in which the more the parent felt they understood the child, the calmer they were able to be in the face of challenges. The child themselves then became calmer, as did the quality of the relationship more broadly:

> ...probably calmer, yeah, calmer...I just feel that I'm understanding him more now, I'm seeing where a lot of the stuff's come from...so I think it's getting a better understanding really, and having to really try and look at a situation and stay calmer myself as well, and I think probably because the calmer I am, the calmer we can keep the situation when he's spiralling out of control (Claire, 262-290).

In particular, mothers talked about the intervention as a catalyst for reflection about alternative ways of spending time together, and realising the value of this family time. Within this, the value of the mothers' position in creating this family time appeared relevant, hinting at what they felt their role in facilitating positive family relationships was:

> Just coming for that one session has made me think a lot more about how good about themselves they could feel if they would work together and play together...I think it does make you more aware of how important it is to try and get them to learn how to be with each other, rather than just telling them off all the time. Cause your instant reaction is "no don't talk to them like that" and "don't do this" and "don't do that". It's not really a very helpful, it's more creating an environment where they can be together, it's more helpful...it has made me more aware of that, that you can turn it around and create this positive space for them to be together (Diane, 396-413).

The idea of having a split family recurred for mothers, referring to feeling forced to spend time separately with each child, rather than together as a family. During the intervention, mothers gained a new perspective on this and became increasingly aware of alternative ways of being as a family:

> I think it's just made me realise that it's nice and important to take some time out to do something like that because together, because we tend to avoid confrontation and we tend to split them up, and I think doing this now, I realise that it's not always necessary (Louise, 127-130).

Mothers also discussed how sibling perspectives were also affected by their participation in the intervention, in particular in terms of providing a different and unique experience compared to the more typical sibling interactions. This shift seemed to have a two-way or mutually interactive impact, as the two childrens' perspectives of each other changed together:

> I think it's made David see Hazel in a more positive way, cause as I said she can be, sometimes I think he finds her as being quite destructive and hard to get on with, umm, and so I think, I think in turn she sees him in a more positive way, cause they did have that time where they interacted together and it was fun, saw each other as in a more positive way (Rita, 212-217).

Mothers further spoke about the way in which participating in the Lego Therapy had opened up new perspectives for their children on the autism spectrum. Diane talked about the intervention as a medium through which her child was able to consider alternative ways of behaving and become more self-aware with regards to his current behaviour:

> Maybe it is to do with the Lego Club, that it's made him more aware that you know, there are certain ways of behaving, there are other ways of behaving other than his way of behaving, and maybe he behaves differently to other people (Diane, 481-485).

2.3.1.3 Deeper and more mutual family relationships.

Mothers talked about how the improvements in communication and understanding helped the family to develop more meaningful relationships together. In particular, mothers felt the sibling relationship became more

settled and easy together, reflecting a deepening of the sibling bond, developing from the shared experience of Lego Therapy:

> When we came it worked very well didn't it, and I think he was quite nice, I think was a bit of a bonding between them, which was nice, so I think he umm, was quite proud of her and she was quite proud of him, and then those couple of sessions together was good for them to do that (Rita, 577-581).

Some mothers noticed an increase in joint play, shared interests and appreciation between siblings:

> I'd say, I think that's improved, they seem closer at the moment...I think that has helped, and I think because they're sitting down and they were giving each other time, rather than the interaction that boys normally have together...I think maybe they appreciate each other a little bit more...I can see that there are signs that they can sit back and appreciate each other and that they can work as a team, I think maybe that's the thing, that you are all doing something together, you know, as a team (Claire, 301-313).

These changes appeared to be generalised to a certain extent to the wider family context, separate from the Lego Therapy sessions themselves:

> I think over Christmas...they seemed to want to interact more than they have in the past, so yeah, I think it did have that knock-on effect, that they, he thought she might cope with doing something, without the board going up in the air (Rita, 222-227).

2.3.2 Child Specific Factors

Mothers identified some other positive outcomes and aspects of the intervention; distinct from, but linked to changes in their family relationships. They focused on changes within the child as an individual as well as the impact of their child's ASD on both the successes of and struggles with implementing Lego Therapy.

2.3.2.1 Impact of ASD

Some mothers spoke about the challenges that their children's needs presented when trying to implement the intervention. In particular, the impact

of the target child's anxiety levels and their resulting need to control the sessions was clear. For example, one parent described how her child's anxiety meant some sessions had to be ended prematurely:

> Mainly Josh's moods really, definitely more his moods and the anxieties that, there's times when it should have been okay and we sort of started it, and then probably several sessions ended after about five minutes, ten minutes, because we couldn't pull them back again...he was just getting too feisty (Claire, 49-57).

This highlights how challenging this intervention was for the family in the context of the child's more global anxiety, and how this anxiety may have been paralleled in mothers' uncertainty about what would happen as each session began.

Mothers spoke in particular about aspects of the intervention itself that they felt made it effective given their children's needs, describing a process in which their children were implicitly learning and improving their skills in a way which fitted with them:

> I think the philosophy behind Lego's very clever and the Lego Therapy, and with the definite roles that they do, I just think it works really well, umm, I think yeah, it does give you a good focus and you just think that instead of just playing, it's playing with a purpose (Claire, 381-385).

Moreover, though the rules were experienced as challenging, they were still welcomed by mothers who found they served to reduce the child's anxiety about what to expect in each session:

> For Hazel it was good because she, because the rules are sort of quite simple, she knew exactly what she was going, whereas if we do other family activities sometimes, other board games, the rules are too complicated for her and she would just get frustrated and not continue, so in that was it worked quite well because she knew exactly what to expect and what she was doing. There wasn't any anxiety about not being doing the right thing (Rita, 155-161).

Another difference between Lego Therapy and more traditional board games was suggested by Claire, who talked about the non-competitive nature of the intervention:

> It's not anything you're going to lose at, you're making something and there's a, a product at the end of it basically, just trying to think how to describe that, but yeah, there's a product at the end of it, it's not like "oh no, you've lost that game", or you know, it's not going to have, umm, make him feel bad about himself, which he doesn't cope well with, sort of feeling like he's losing again, so it's a positive (Claire, 392-398).

This idea of being able to do something proactive to aid their children's skill development in a way that the children enjoy was especially meaningful for mothers, perhaps in the context of continuously trying new and often challenging strategies with limited success:

> It's also given us an hour a week that we're sat focusing on something that both the boys love and they think of as a great game but it's in fact improving their communication and improving their relationships without them realising (Lucy, 505-508).

2.3.2.2 Child specific developments.

Mothers identified a range of changes they had seen in their child on the autism spectrum over the course of the intervention. These included reduced anger and aggression, improved ability to focus, concentrate and listen to instructions, increased flexibility, more scope for abstract thinking, improved communication skills, reduced impulsivity and higher self-esteem. The extent to which these changes were generalised outside of the Lego sessions was variable, as Claire talked about the improvements being session-specific:

> Definitely his communication skills, they were getting better towards the end. More in the session than obviously carrying it on necessarily after, but certainly, his verbal ability during the session was definitely better. You know, in terms of everything really, you know, the whole sort of praising and they way he was using those words, the descriptive words he was using, and they way he was you know, he

> was managing to do that, I would say, definitely, definitely better (Claire, 560-566).

However, one mother talked about the impact of the intervention on her son's social skills more broadly and the tangible impact it had on his attainment outside of the sessions, demonstrating the varying impact of the intervention:

> That's really improved, umm, he's a lot more able to talk to people and to, just listen and react appropriately...he actually got an award from his gymnastics club on Saturday night, Friday night, umm, for effort and enthusiasm, which was brilliant, and I think it's because he's calmed down, he's not so grumpy, because he was a bit, either hot or cold at doing things, and he seems to be managing other children better...so it has improved his social skills definitely (Lucy, 649-661).

Mothers also highlighted how a snowball or circular effect appeared to occur, in which the child's increased calmness and improved communication skills created space for more mutual respect, shared time and genuinely listening to the child's voice, again facilitating calmness in the mother-child relationship:

> He's a lot calmer, he's not raging as much, so I think there is more respect for me and I'm respecting him more, I'm sort of trying to treat him not as an adult, cause he's not, but with that kind of respect for his opinions and his thoughts, which I think's much better and just calmer, we are a lot calmer (Lucy, 338-343).

Mothers also focused on reductions in aggression and fighting between the siblings and a greater acceptance of each others' individual differences. This included becoming a little more flexible with each other and as a result having a calmer relationship, again demonstrating the interactional and snow-ball effect of the changes experienced in the family relationships. Many mothers described their role in the family as a facilitator and mediator of relationships, and this reduction in tension may have thus been particularly meaningful from their perspective.

2.3.3 Intervention Specific Factors

Whilst mothers talked at length about the changes experienced in their family relationships and in their children, they also experienced some barriers to implementing the intervention and expressed some ambivalence about its impact.

2.3.3.1 Time.

Time presented a particular barrier to mothers trying to implement the intervention, both in terms having enough time and finding what they perceived to be the right time for their children. For one parent, this meant not implementing the intervention at all, as she struggled to balance family life and managing a child on the autism spectrum in the context of little external support and a relatively recent autism spectrum diagnosis:

> I think there's too much to cope with, with all the history, plus the last nine years, plus trying to come to terms with all this, plus trying to find a way to move forward, and then there's trying to deal with all three of them, and doing it on your own [laughs], you know, it's quite trying, but yeah, you know when you're left on your own to do it, it's quite hard (Diane, 669-673).

Diane's laughter, alongside many of the other mothers' use of humour when discussing difficult experiences, serves to highlight the fine balance of family life for this group of mothers and the potential difficulty of trying to fit in another strategy or activity to help their children.

Context was important for other families too, as they talked about the impact of external events, such as difficulties at school, on their ability to implement the intervention effectively and to get the most from it for them and their children:

> It's a shame really, because I think, given the circumstances, if the circumstances had been different, and Josh hadn't been going through his issues, it probably would have had a bigger impact...if things had all been calm with him, we would have had a lot more sessions and probably would be a bit further on (Claire, 211-219).

This emphasises the importance of a settled context in order for families to benefit the most from this intervention, and hints at Claire's possible yearning for different circumstances more broadly as she talks about a wished-for alternative outcome. This also suggests the mothers were able to retain a sense of hope that more change and progress may always be possible; though in Claire's family context, the experience of Lego Therapy seems to be tinged with disappointment about the extent of the impact.

2.3.3.2 Intervention ambivalence.

Most mothers expressed some uncertainty about the impact of the intervention compared to the impact of other factors in the wider context at the time of the intervention. However, this emerged alongside a determination and desire to continue the intervention after completion of the research study, demonstrating the ambivalence mothers had about the intervention.

Louise talked about the likely combination of factors involved in the changes she experienced within her family and her uncertainty about which elements were most instrumental in this:

> I don't know whether that's just the Lego, I think it definitely has helped during the sessions, that we were calm and patient, obviously there was no frustration there, but it's just because Robert generally seems a lot happier, that obviously there is less friction anyway...it's probably a combination, yeah, probably a combination yeah of him

> generally being happier and also I think yeah, maybe the Lego (Louise, 264-276).

This ambivalence perhaps reflects the reality of a home-based, family-based intervention. Louise expressed some reticence about attributing too much value to the Lego Therapy; indeed the mothers as a group were inclined to attribute at least some meaning to the wider contextual factors when considering the changes they described in their child and their family relationships.

Given the uncertainty of some mothers about the specific impact of the intervention, it was interesting to note that all mothers intended to continue the Lego Therapy at home after completion of the required sessions, reflecting in particular on the children's enjoyment of the sessions:

> It's been a really positive experience and they actually want to carry it on (Lucy, 12-13).

Mothers talked about the benefits they hoped for in the future in terms of having fun, engaging their children in something helpful and productive, and as having found a way to spend constructive family time. This suggests that for the mothers in this study, Lego Therapy had in some way been internalised into their range of strategies which aim to foster their children's development and the development and maintenance of their family relationships:

> I think this is the, the Lego Therapy, the reason I wanted to do it was because I thought it was a positive, practical thing, we can do it, they can work together and from that, something positive can come out of it (Diane, 326-329).

This intent to continue the intervention hints again at the hope for the future that the mothers consistently carried across the intervention, reflecting perhaps a more global coping strategy for them in the face of the broader challenges having a child on the autism spectrum presents.

2.4 Discussion

This study explored the maternal lived experience of implementing Lego Therapy and in particular this experience within the context of their family relationships. Mothers reflected on the impact the intervention had on family communication, their relationships and perspectives, as well as on the child themselves. They also discussed the impact of the child's ASD, and the ambivalence about and challenges they experienced during the intervention.

2.4.1 Family Specific Factors

Within the family, mothers focused on the improved communication and understanding they felt they had gained from the intervention. This is in line with the previous Lego Therapy studies (LeGoff, 2004; LeGoff and Sherman, 2006; Owen et al., 2008) in which children participating in peer groups developed greater social competence and presented with reduced autism-specific social difficulties, including initiating and maintaining social interaction and communication for longer periods of time. Rao, Beidel & Murray (2008) argued that social communication skills are fundamental for the development of relationships, and thus it follows that an intervention which has previously been found to improve communication skills also improved relationships. Vangelisti (2004) suggested that when family

members communicate, they enact their relationships and thus create mental models of family life which are maintained over time, underpinning the value of communication for relationships and perhaps accounting for the importance of improved communication for the mothers. This change may have also impacted on their role as a mother, meaning a reduced need to intervene in misunderstandings and arguments between the siblings.

The interactive and interdependent nature of the improvements in family relationships echoes family systems theory (Goldenberg & Goldenberg, 2003; Seligman & Darling, 2007; Turnbull & Turnbull, 2001) which argues that all sub-systems within a family need to be considered during an intervention. Within the current study, this was facilitated by inclusion of not only the mother-child dyad, but also siblings. Moreover, the ability of some mothers to extend their learning to father-child and marital relationships highlights the potential for Lego Therapy to work closely with a family systems framework and develop the interactive and interdependent changes for a whole family system. Indeed, interventions for children who are on the autism spectrum have not directly targeted family relationships, or have done so only at an individual or couple level (Seligman & Darling, 2007), which is in contrast to the novelty of applying a whole family approach to this population in the current study. Though it is acknowledged that fathers were not directly included in the study, the experience of mothers in being able to transfer some of their learning to fathers' family relationships highlights just how powerful Lego Therapy may be from a family systems perspective. Simon (2004) reported that research around family therapy with this

population is scant, and that this may be due to the dominant professional explanation for difficulties being focused on cognitive failure or organic causality.

Indeed, Lego Therapy offers families a non-stigmatising intervention to improve family relationships, which is motivating for children and empowering for parents. Attwood (1998) argued that parents want treatments which empower them to manage their own children and which emphasise the principle of collaboration between parent and professional, and the experience of the mothers in the current study suggests Lego Therapy may be one way to begin this process.

Mothers reflected on how direct involvement in the intervention in a naturalistic home setting allowed them to learn more quickly about their child and to generalise their learning to other family settings. Williams and Wishart (2003) found that a positive experience of family involvement in a social communication intervention was related to a higher level of perceived intervention efficacy and this may have contributed to the mothers' positive experience. Sofronoff, Attwood and Hinton (2005) also support the inclusion of parents in interventions with children on the autism spectrum, reporting that being involved in a Cognitive Behavioural Therapy intervention with their children with Aspergers Syndrome helped parents to feel more competent in the content of the intervention and therefore more able to support their child; a process which seems to be mirrored in the current study.

Being taught how to implement Lego Therapy in the training sessions and then being able to use it flexibly with their children was an empowering experience for families, which is particularly important given the research showing that empowering and strengths-based approaches have been most effective within family services (MacLeod & Nelson, 2000) and are advocated in the National Service Framework for Children, Young People and Maternity Services (2004).

The positive outcome of including siblings supports LeGoff's (2004) positive experiences of including siblings as helpers. It is not clear whether this directly facilitated the target child's learning, as Schertz and Odom (2007) suggested occurs when family members are included in interventions, but the positive shared experience did seem to encourage children to spend more time together and develop their relationships further, which may have then provided additional opportunities for extending their learning. Regardless of the means, the increases in intimacy, pro-social behaviour and nurturance mothers noted in the sibling relationship support the inclusion of siblings in family interventions, particularly in light of Kaminsky and Dewey's (2001) findings that these factors are usually diminished within the sibling relationships of children who are on the autism spectrum.

Mothers' views of the changes in perspective they, their target child and their sibling experienced can be considered in light of the growth and resilience literature discussed in Peckett, MacCallum and Knibbs (2011). King, Barker, Rosenbaum, Zwaigenbaum and Bates (2009) found that the optimistic and

accepting perspectives adopted by families of children with developmental disabilities provided them with increased hope, meaning and control. It is possible that Lego Therapy provided a means through which families were able to engage in this ongoing process of reflecting on family culture and relationships, potentially contributing to their personal and family growth.

The experience of changed sibling perspectives is particularly relevant to the literature, suggesting siblings of children on the autism spectrum hold more negative perceptions of sibling relationships compared to control children (Bagenholm and Gilberg, 1991). Though these changes were only from the maternal reports, the findings suggest Lego Therapy may be of particular value when considering the impact for siblings of having a brother or sister on the autism spectrum, providing an opportunity for developing alternative views of each other. This can be applied to all the changes in perspectives experienced and again echoes the principles of systemic and narrative models, given the emphasis these approaches place on the opening up of alternative perspectives and finding exceptions to previously accepted views (e.g. Freedman & Combs, 1996; White & Epston, 1989).

It is not evident to what extent Lego Therapy presents a unique experience within which family perspectives can be considered, or whether this is a possible outcome of spending enjoyable time together as a family more broadly. Mothers reflected on realising the value of this family time and it may be that the intervention provided a relatively simple and motivating means through which a previously difficult goal became possible.

2.4.2. Child Specific Factors

The difficulty mothers experienced in implementing the intervention when their child was anxious was one of the main barriers. This is unsurprising, given the elevated rates of anxiety disorders and symptoms in children on the autism spectrum (e.g. Green, Gilchrist, Burton & Cox, 2000; Kim, Szatmari, Bryson, Streiner & Wilson, 2000). However, LeGoff (2004) found that the additional needs of children with diagnoses such as anxiety disorders, depression or adjustment difficulties did not present obstacles to participating in Lego Therapy groups. It is possible that with these especially anxious children a higher ratio of trained facilitators is required to ensure the smooth running of the intervention, rather than just the parent. This raises the question of timing; whether to wait until the child is more settled to implement the intervention, or attempting to carry it out with a view to it alleviating some of the child's difficulties.

Despite these difficulties, the rules were cited as a helpful factor for some families, in line with the broader literature about the appeal of rules and structure for children on the autism spectrum (e.g. Dodd, 2005). Moreover, the children's passion for Lego was repeatedly mentioned as helpful to the implementation of Lego Therapy, in line with LeGoff's (2004) initial observations that children on the autism spectrum appeared to be particularly drawn to Lego. Mothers' experience of the value of this passion in implementing the intervention supports the argument for using a child's choice of materials in order to improve motivation and engagement (e.g.

Attwood, 1998; Greenspan & Wieder, 1998; Koegel, 1995). Mothers also reflected on the way Lego Therapy provided a way for their children to learn and develop implicitly, at times without explicit awareness for the child of the goals of the intervention.

Distinct from the impact on their relationships, mothers also discussed the impact of the intervention on the target child, focusing on reductions in anger, aggression and impulsivity and improvements in flexibility and concentration. This mirrors previous Lego Therapy research (Owens et al., 2008) in which a reduction in maladaptive behaviours was found following participation in a peer-group intervention. Mothers reported increases in more pro-social and positive characteristics such as being helpful towards siblings and having higher self-esteem. The more open focus of this study, compared to the previous specific behaviour-focused studies, allowed a more balanced and strengths-based approach to emerge.

2.4.3 Intervention Specific Factors

The extent of the pressures mothers are under to balance all the aspects of family life was very apparent, and for some families attempting to implement a home-based intervention with relatively little support brought additional stress. Williams and Wishart (2003) found that parents of children with autism implementing a highly intensive home-based intervention experienced this as a big pressure on their time. However, other drawbacks reported such as having less time to spend with other children, the other children feeling left out and the intervention dividing the family were minimised in the current

study as a consequence of its inclusive nature. The potential stress that implementing a home-based family-led intervention may cause needs to be balanced against the ecological validity of this approach, compared to a more structured, clinician-led and clinic-based intervention which may be less empowering for families but offers more direct support.

Mothers' ambivalence about the intervention impact is interesting in light of the positive themes to emerge. This ambivalence could reflect mothers' attitudes more broadly about the impact of external interventions on their lives and their children. Alternatively, it may be that the short duration of the intervention and the complex pattern of factors involved in their lives make it difficult for mothers to untangle what had the most impact for them. Either way, this seems to reflect a curiosity and uncertainty in mothers about the impact of the intervention.

This aforementioned curiosity may be partly responsible for the mothers' intent to continue with the intervention following their participation in the study, perhaps to monitor its impact on their family lives. The hope that mothers expressed about the potential impact the Lego Therapy could continue to have may link to the relationship improvements already experienced. Kausar, Jevne & Sobsey (2003) found that increased family cohesion was associated with the development of a hopeful attitude, and it is possible that the improvements experienced in family relationships helped families to maintain this sense of hope.

2.4.4 Methodological Considerations

Given the home-based, family-led nature of the intervention and the inexperience of families, it was difficult to ensure treatment fidelity, and families did make adaptations to suit their needs. Thus, the impact of the intervention needs to be considered within a broader Lego Therapy model, rather than as related to specific potentially flexible aspects of it, such as length of session or number of sessions. In addition, the current intervention was much briefer than that used in previous Lego Therapy studies (LeGoff, 2004; LeGoff & Sherman, 2006; Owens et al., 2008) and so the impact cannot be directly compared.

The sample held some limitations; only mothers were interviewed and thus the paternal experience is still unknown. The sample size is relatively small and was generated using one service in one geographical area, which may mean the results are not applicable to other larger populations. Willig (2008) acknowledged that qualitative research can be criticised more broadly as lacking external validity, but points out that the purpose of it is not to identify globally applicable cause and effect relationships, but to generate insights into the dynamics and experiences of a small number of cases. Indeed, locating the intervention at home in a family setting gives the study high ecological validity, suggesting the data do reflect the genuine lived experience of mothers.

Finally, the use of the maternal perspective rather than the children's perspective to consider the impact on the sibling relationship could be

questioned. Though the current study makes no attempt to suggest that the child's perspective is directly represented, it remains to be seen whether the themes that mothers emphasised would be reflected in the childrens' experience if they had been directly consulted. However, given that it was the mothers who acted as facilitators of the intervention and it is this experience of implementing the Lego Therapy at home and the subsequent impact on the family that was of paramount interest to the study, this choice of participants is justifiable.

2.4.5 Clinical Implications

Taken as a whole, the findings are supportive of the use of Lego Therapy in families at home, with a particular emphasis on improvements in family relationships and child-specific characteristics. However, the challenges encountered highlight the importance of the right context in order to maximise the intervention impact, and in fact to ensure families do not experience it as another failure. One way to reduce the potential stress associated with this intervention could be to draw together families who are using the Lego Therapy at home into a group at some stage, perhaps mid-way through the intervention period, to help parents feel more supported and offer a generalisation opportunity for the children.

Overall, the findings highlight the value of considering each family on an individual basis to ensure any support they require enhances the efficacy of the intervention, for example having a clinician attend a session at home to help facilitate in the first instance. Families whose wider context was more

settled seemed to benefit the most from this intervention, and it may be that it is not suitable for application with families whose context is more chaotic or whose child is experiencing more significant difficulties.

For those families who are able to cope, Lego Therapy in families seems to provide a relatively simple way to engage their children on the autism spectrum in an intervention that potentially has a very broad impact. Given that the intervention focuses on building strengths, rather than alleviating problems, it fits well with the strengths-based approach often applied in systemic or solution-focused therapy (e.g. de Shazer & Dolan, 2007; Lethem, 2002) and may provide a low-level, non-stigmatising and flexible alternative to more formal systemic approaches. This is particularly relevant to this population, who may be more acclimatised to individual-focused and problem-saturated narratives around their child and family (Lawthom & Goodley, 2005).

More broadly, the findings support the inclusion of parents and siblings in interventions for children with autism, given the benefits mothers reported for their family relationships and family perspectives. This has implications for clinical time and service provision. If clinicians are able to train families in the use of Lego Therapy, rather than invite only children to participate in clinic-based social skills or relationship-based interventions, this may free up some clinical time that would otherwise have been spent facilitating these. This has consequences for increasing access to services, though this always needs to

be balanced against providing the appropriate approach for the family, which is most likely to be a combination of interventions at different levels.

2.4.6 Future Research

Given the difficulty comparing the current qualitative findings with previous quantitative studies (LeGoff, 2004; LeGoff & Sherman, 2006; Owens et al., 2008), a mixed method design may be useful to facilitate synthesis of the literature more broadly and to compare objective measures of change with the subjective experience. Comparison of the impact of a clinic-based Lego Therapy family intervention versus a home-based intervention would be useful in terms of planning effective service provision. Indeed, the family experience of implementing home-based interventions in general warrants more research.

LeGoff (2004) found evidence that the gains in social competence were generalised to natural settings such as unstructured, unsupervised time at school. The current study did not seek to establish whether the impact of the intervention was generalised to settings outside of the home or non-family relationships and so this would be a useful focus for future research, particularly in terms of longitudinal effects.

More research is required to investigate how family-based Lego Therapy can best be implemented with those families who are more vulnerable or who have additional needs, for example in tandem with individual sessions, as in LeGoff's (2004) study. It would also be useful to explore how Lego Therapy

compares to other interventions designed to improve family relationships in terms of impact and family experience. It will be important in future research to incorporate other family members' perspectives to a greater extent, including the child's experience, to ensure the intervention is truly family-centred. Research considering how Lego Therapy could be integrated more closely with family systems theory and family therapy models more broadly would also be useful, given its potential to have a wide reaching impact and links to strengths-based approaches. Finally, given the novelty of this area, more research with larger samples in the same population is warranted to help build a more comprehensive picture of the experience and impact of Lego Therapy with families.

2.4.7 Summary

This research explored maternal experience of implementing Lego Therapy in families in the home. Emerging themes included developing communication, deeper family relationships and gaining new perspectives, as well as the impact of the child's ASD on the experience of implementing the intervention and child-specific developments. Time and ambivalence about the impact of the intervention were also important themes for mothers. The findings are supportive of previous Lego Therapy studies (LeGoff, 2004; LeGoff & Sherman, 2006; Owens et al., 2008) and have implications for clinical practice in terms of engaging this population of children, empowering parents and providing effective, individualised interventions.

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Chapter Three

Engaging in research with families of children on the autism spectrum: Reflections on the impact of individual differences

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Paper prepared for submission to Clinical Psychology Forum (see Appendix A for submission guidelines)

Abstract

Reflections on the experience of conducting an intervention study with families of children on the autism spectrum are presented, focusing on the impact of family individual differences. The value of family-centred approaches is considered within this, alongside some personal reflections.

3.1 Introduction

This paper presents my reflections on the process of conducting research with families of children who are on the autism spectrum as part of the Clinical Psychology Doctorate. The empirical paper explored parental experiences of a family Lego Therapy intervention at home and the impact of this on their family relationships, whilst the literature review focused on positive growth in parents of children with developmental disabilities. Themes of individual family differences and the balance between the roles of researcher and clinician will be discussed. The ethics of gaining assent from children will also be considered.

3.2 Individual Family Differences

Families who participated in the research shared a number of common experiences, both in their family relationships and also in their experience of Lego Therapy, discussed in detail in Peckett, Knibbs & MacCallum (2011). Alongside this however, the families' individual differences were highlighted throughout the research process. Differences were clear at every stage of the process; at recruitment in terms of interest level and ease with which families could be contacted; in the training sessions as each family interacted together in unique ways; and during interviews, in the inevitably unique stories mothers shared about their family relationships and their experience of the intervention, including the adaptations each family made to suit their particular needs.

3.2.1 Context

The external context appeared to be particularly variable between families, yet carried significant weight in terms of the impact of Lego Therapy on their family. For example, one mother had chosen to home-school her children and spoke about the importance of their whole lifestyle on her ability to integrate Lego Therapy into their lives in a flexible way which suited them. In contrast, another family was not able to implement the intervention within the timescale required by the researcher (4 months), citing a lack of overall time within the family week as one of the main issues encountered. Families also talked about time in terms of the "right" or "wrong" time. Two families highlighted times when the child on the autism spectrum was struggling at school and the impact of this on their ability to implement the intervention; for example needing to shorten sessions due to the child's heightened anxiety. However, another family discussed how starting the Lego sessions coincided with a change of school and the child becoming more settled in general.

3.2.2 Stress and Family Support

These differences arguably also highlight variability in the stress levels of the participating families. Mothers who struggled more during the intervention also talked more about the difficulties balancing the many demands of family life, and it is possible that the intervention served as another pressure for these mothers, rather than as a helpful intervention for their family. Differences in family composition seemed to further

impact on mothers' ability to manage and cope with this stress. Many parents reflected on the value of support from their partners and extended family in coping with having a child who is on the autism spectrum and on their ability to implement the Lego sessions, including talking through any difficulties with them as well as providing support to care for younger children whilst they were facilitating the Lego sessions with the older children.

However, for other mothers, the Lego intervention further highlighted their sense of isolation from their extended families or their aloneness as parents and made all the more poignant how much they were balancing. One mother in particular considered how the experience of having children brought back upsetting memories of her own childhood and made these difficulties present in her adult life again as she reflected on the absence of her extended family in the lives of her children now. This shows how the lack of family support may have a spiral effect for some families, in which their sense of isolation adds to their stress levels and sense of not coping, which in turn is likely to limit the extent to which they are able to implement new interventions for their children.

3.2.3 Intervention Adaptations and a Family-Centred Approach

Family individual differences were also evident in the adaptations each family made to the Lego Therapy sessions to maximise its impact for them. For some families, this meant keeping to a strict routine and schedule, while for others it involved the willingness to be flexible

according to when the children were most receptive to engaging in the sessions. Some families lengthened sessions to ensure children were able to complete as much of the model as they wanted to within the session, whilst others shortened sessions due to limits on the children's concentration span. Families also adapted the roles to suit their family needs at times, for example when one child did not want to engage in a particular session, the parent took on two roles to ensure the session could still go ahead.

This suggests that while standardised or structured interventions may be a useful guide for families using home-based interventions, the individual differences in family characteristics need to be taken into full account to ensure families reap the most benefits. Keen and Knox (2004) discussed the value of a family-centred approach to interventions with children on the autism spectrum and with challenging behaviour. They suggested that families being the base for the intervention may help strengthen the family unit in a way that helps provide ongoing support for the child on the autism spectrum, but also enhances the quality of life for all family members, as seemed to occur for the families who had adequate support and were able to make family-specific adaptations within the current study.

3.2.4 Social Comparison Processes

Despite the broad individual differences across participants, it was interesting to note that many families expressed interest in or concern

about their similarity to other families. All participants asked questions about how they compared to the other families, for example in terms of their experience of the Lego Therapy sessions but also in terms of their family relationships. Though exploring this issue was outside the remit of the empirical paper, this may reflect something about the experience of participating in family research for parents more broadly, in particular an intervention study.

It is possible that families felt more directly compared or judged regarding their experience given that not only were they involved in a relatively novel intervention, but also they held significant responsibility for its implementation compared to more individual, clinic focused interventions. This may also reflect an uncertainty more broadly of where they and their family fit into society. Making comparisons to others may be an attempt to find a sense of similarity and belonging with a group of families with some similar experiences to them (Festinger, 1954; Turner, 1987), in a context of being different to the predominant family model in which there are no children with disabilities.

Indeed, the experience of caring for a child on the autism spectrum may include regularly taking an advocate role for their child and their family, within a wider context in which their children on the autism spectrum may be feared, marginalised or misunderstood (Stillman, 2009). Though this is likely to present an additional challenge for families, it also links to positive growth in parents of children with developmental disabilities; as

Scorgie and Sobsey (2000) noted, parents of children with developmental and physical disabilities reported a greater ability to speak out on behalf of their children over time and identified this as a personal transformation. Thus, whilst mothers compared themselves to others during this study, for some this may have been part of an empowering experience in which their sense of agency was enhanced. Some of the participating families felt they had discovered a new way of being for their family more broadly, which suggests that the intervention could be a family-centred and empowering experience in the right context.

3.3 The Balance Between Research and Clinical Roles

Throughout the research process, it was often difficult to balance the roles of researcher and clinician. Though the empirical study was undertaken in the role of researcher, it involved implementing a clinical intervention using the clinical expertise gained in a clinician role as a Trainee Clinical Psychologist.

This proved particularly challenging during the interview process, in which it was difficult not to use the person-centred counselling skills that Clinical Psychology training encourages, instead of remaining neutral and waiting for the participant to put their experience into their own words. This was an ongoing learning process however, as it became clear that at times paraphrasing and summarising the participants' experiences meant the transcript content was less rich and though an understanding of the experience had been gained, it had been influenced by the researcher's

perspective, and was not necessarily transparent in the transcript itself. Though within Interpretative Phenomenological Analysis (IPA), the researcher's stance is acknowledged, this ideally only becomes apparent at the analysis stage, once the data has already been gathered from the participant's perspective (Smith, Flowers & Larkin, 2009).

This role conflict also presented a challenge when considering that this research involved implementing an intervention, rather than simply gathering information regarding an experience participants had already had, independent of the research. Although no families were encouraged to participate if it was felt the intervention would be detrimental to them, the exploratory nature of the study meant the outcome for them was unknown at the outset. This presented an at times uncomfortable position of asking participants to engage in a potentially challenging experience with no guarantee of benefit.

While this is not necessarily different to the experience of other therapeutic interventions that families may take part in at a Child and Adolescent Mental Health Service (CAMHS), there was an awareness that whilst the research may be useful for participants, it was also a required element of the professional qualification of the researcher, and so potentially held more value for the researcher than the participants. Indeed, in a clinic setting, individual adaptations and a family-centred approach would be paramount, yet within the research setting it was important to balance this with a standardised approach to ensure the

research was examining the experience of the families of implementing the same intervention as much as was possible. The nature of the intervention within the participants' family homes seemed to contribute to this discomfort, as they were asked to integrate this intervention into their home lives, rather than only need to sacrifice a shorter amount of time for a one-off research interview, as in some other studies of family experiences.

3.4 Ethical issues

Though the ethics of the study overall were carefully considered during the process of applying for ethical approval, the researcher was struck by the principle of seeking children's assent during the process of actually doing so. Given that the parental consent was considered sufficient for participation in the study, and seeking children's assent was considered good practice (British Psychological Society, 2009), rather than a requirement, it felt at times uncomfortable to see parents encourage their children to sign the assent sheet (Appendix I) even when it was not always clear they either understood the process or were willing to engage with it. Indeed, the researcher's own eagerness to recruit participants may have meant she was complicit in this, rather than questioning this.

Though most of the children seemed content to participate, two children in particular expressed some reluctance about it, stating that they always have to do what their parents want without being asked themselves. These children did go on to participate, but it left a question hanging

about the utility of seeking children's assent, if indeed their parents are ultimately making the decision on their behalf and the child's understanding of it was not always clear. Here, it was the researcher's responsibility to ensure both understanding and genuine assent, and it is likely that her desire to recruit participants within a limited timescale, and her relative inexperience in seeking either consent or assent for research impacted on this. In future, perhaps more time should be allowed for recruitment and more thoughtful consideration given to the role of children's assent in this type of research. This is especially the case given the communication difficulties and potential vulnerability of this particular population of children.

3.5 Personal reflections

Alongside the pertinence of family and individual differences in family level interventions with this population, the research process also prompted some personal reflections. In particular, as a novice to IPA research, and indeed qualitative research, it was interesting and often challenging to shift to a more interpretative stance, including taking account of the researcher perspective, particularly when compared to quantitative research in which the results can initially appear clearer cut. At times questions were raised about the value or correctness of the researcher's interpretations and perspectives, which may have in part been linked to the pressure to get something right, given that the research was being assessed as part of a Doctoral thesis. Again, the impact of individual differences became apparent in terms of the

potentially varying interpretations different researchers may draw when analysing the same data. However, deeper emersion into, familiarity with, and wider reading about the IPA process helped build the researcher's confidence in the analysis.

The experience of interviewing mothers was also beneficial to the researcher in her clinical role; to bear witness to the stresses and joys of implementing an intervention in a way which perhaps a clinical role would not allow time for was a privilege. The lessons learnt about the individual differences in the day to day life of families in this population will be taken forward into future clinical work in which families are asked to make changes to their family culture, implement difficult interventions or simply speak about their experiences.

3.6 Conclusions

To summarise, reflecting on the process of research with families of children who are on the autism spectrum highlights the wide range of individual differences that are present and the need to work alongside this. This means celebrating and encouraging individual and family differences, rather than trying to fit a family to the intervention, in line with a family-centred systemic approach (Keen & Knox, 2004). This may also mean reflecting on our own personal and professional views of and conflicts with individual difference to ensure this stance can be adopted to the benefit of families as much as possible, and perhaps considering the

role of Clinical Psychology on a wider community level to help target stigmatisation and resistance to difference.

Future research could seek to explore what the experience of conducting an intervention at home is like for families. The potential experience of self-evaluation and comparison in this process and the impact of this on the impact of the intervention itself could also be investigated.

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Appendix A

Journal Guidelines for Authors

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Author Guidelines

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The *Journal of Applied Research in Intellectual Disabilities* is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

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2. ETHICAL GUIDELINES

Acceptance of papers is based on the understanding that authors have treated research participants with respect and dignity throughout. Please see Section 2.2 below.

2.1 Authorship and Acknowledgements

Authorship: Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL authors must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship.

It is a requirement that all authors have been accredited as appropriate under submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

Acknowledgements: Under Acknowledgements please specify contributors to the article other than the authors accredited. Please also include specifications of the source of funding for the study and any potential conflict of interest if appropriate. Suppliers of materials should be named and their location (town, state/county, country) included.

2.2 Ethical Approvals

Research involving human participants will only be pubished if such research has been conducted in full accordance with ethical principles, including the World Medical Association Declaration of Helsinki (version, 2002 www.wma.net) and the additional requirements, if any, of the country where the research has been carried out. Manuscripts must be accompanied by a statement that the research was undertaken with the understanding and written consent of each participant (or the participant's representative, if they lack capacity), and according to the above mentioned principles. A statement regarding the fact that the study has been independently reviewed and approved by an ethical board should also be included.

All studies using human participants should include an explicit statement in the Material and Methods section identifying the review and ethics committee approval for each study, if applicable. Editors reserve the right to reject papers if there is doubt as to whether appropriate procedures have been used.

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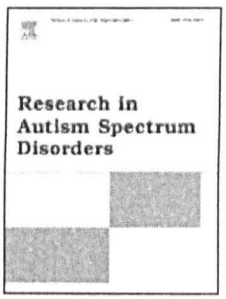
RESEARCH IN AUTISM SPECTRUM DISORDERS

AUTHOR INFORMATION PACK

TABLE OF CONTENTS



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DESCRIPTION

Autism Spectrum Disorders are problems of social skills, empathy, and effective use of language for communication. Many challenges exist to better identify and treat the range of symptoms these persons display. These issues are compounded by the fact that upwards of 70% of these individuals have an intellectual disability and many also evince challenging behaviors such as self-injury and/or aggression, and comorbid mental health conditions such as depression or anxiety disorders. Furthermore, while great advances are being made with young children with the potential for even greater gains, little is know about assessment or intervention with teenagers and adults.

Research in Autism Spectrum Disorders (RASD) will publish high quality empirical articles and reviews with a primary focus on applied topics. These areas will include but not be limited to diagnosis, incidence and prevalence, methods of evaluating treatment effects, educational, pharmacological, and psychological interventions across the life span. The primary audience for the journal will be researchers and clinicians with advanced degrees in the areas of mental health, education, communication disorders, rehabilitation, and allied disciplines.

AUDIENCE

Researchers and clinicians with advanced degrees in the areas of mental health, education, communication disorders, rehabilitation and allied disciplines.

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- Telephone and fax numbers

All necessary files have been uploaded
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Further considerations
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Guidelines for Contributors

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Give a 40-word summary (maximum) at the beginning of the paper.

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Ask readers to request a copy of your questionnaire from you rather than include the whole of it in the article.

Please e-mail one copy of your completed article to Sue Maskrey and also post one to her:

Sue Maskrey, CPF Administrator, Clinical Psychology Unit, University of Sheffield, Sheffield S10 2TN

Appendix B

Literature Review Summary Table

Reference	Population	Sample	Aims	Method	Analysis	Results	Implications
Parental Perceptions of Positive Growth Factors							
Taunt & Hastings (2002)	Families of children with developmental disabilities aged 1-24 years	47 parents	Explore parents' perceptions of positive effects of having child with developmental disability.	Semi structured interview (14 parents) & an electronic survey (33 parents).	Content analysis	A range of themes related to positive growth emerged.	Positive perceptions an intervention goal in parental work.
Myers, Mackintosh, & Goin-Kochel (2009)	Parents of children on autism spectrum aged 2-21 years	493 parents	Listen to parents' words on impact of raising a child with autism.	Web based parent questionnaire.	Content analysis	Themes related to positive growth emerged. Dialectical viewpoint; finding meaning whilst acknowledging the difficulties.	Meaning-making highlighted in overcoming adversity.
Scorgie & Sobsey (2000)	Parents of children who have developmental and/or physical disabilities aged 3-25 years	15 parents in qualitative phase, 80 primary carers in quantitative phase.	Explore transformations in parents of children with disabilities.	Interview & survey.	Qualitative & quantitative data analysis	Personal, relational & perspectival transformations identified.	Positive perceptions an intervention goal in parental work. Sharing findings with families for validation and hope.
Belief Systems							
King, Zwaigenbaum, King, Baxter, Rosenbaum & Bates (2006)	Families of children with autism or Down Syndrome (ages unknown)	19 "key informants" – 15 parents & 4 service providers	Explore world views, values & priorities of families & how beliefs change over time.	Focus groups	Qualitative analysis	Parents gained higher sense of coherence & increased control through changes in world views, values & priorities.	Sharing findings with families for validation and hope. Framework for service provision -

							importance of family belief systems.
King, Baxter, Rosenbaum, Zwaigenbaum & Bates (2009)	Parents of children on the autism spectrum (ASD) or with Down Syndrome (DS) aged 6-8 years & 15-17 years	Parents in 16 families	Examine family belief systems in parents of children with ASD or DS.	Parent interviews plus parent-report questionnaires (Family Environment Scale & the Family Impact of Childhood Disability Scale).	Grounded theory & descriptive statistics	Families adopted perspectives of optimism, acceptance, & appreciation – provided hope, meaning and control.	Sharing findings with families for validation and hope. Framework for service provision - importance of family belief systems.
Sense of Coherence							
Retzlaff (2007)	Families of children with Rett Syndrome	6 families	Explore resilience related narratives of families living with Rett Syndrome.	Interview – 3 families with high coherence & 3 families with low coherence (Family Sense of Coherence Scale).	Grounded theory & narrative analysis	Social support & changes in family world view important for family adaptation. Emphasised in families with high coherence.	Sharing narratives to increase resilience & growth. High sense of coherence may facilitate growth.
Religion & Spirituality							
Sorensen Marshall, Frost Olsen, Mandleco, Taylor Dyches, Allred & Sansom (2003)	Latter Day Saint Families with a child with a disability aged 1-18 years.	32 parents	Explore spiritual belief & religious support among families from this population.	Interview	Descriptive analysis	Having a child with a disability was a spiritual experience & part of a positive adaptation process.	Religious beliefs valuable in helping families to adapt.
Tarakeshwar & Pargament (2001)	Families of children who have autism aged 4-24	45 parents	Consider role of religion in coping process	Parent-report questionnaires plus 21 parents	Correlations & hierarchical	Use of "positive religious coping" was associated with stress-	Consider encouraging religious coping

	years		in families of children with autism.	interviewed	regressions & qualitative coding.	related growth. Religion offered meaning and informal social support.	to gaining strength & grow.
Skinner, Correa, Skinner & Bailey (2001)	Parents of Mexican & Puerto-Rican origin, living in the USA, who had children aged 6 years or less with a developmental disability	250 parents	Examine religious beliefs & practices in parents of Mexican & Puerto-Rican origin who had children with developmental disabilities.	Semi-structured interviews & questionnaires	ANOVA & thematic analysis	Faith brought parents strength & hope. Religion provided a way to make meaning of the child's disability.	Research required on role of religion as a mediator of emotional states & the use of "religious counselling".
Hope							
Kausar, Jevne & Sobsey (2003)	Parents of children with developmental disabilities aged 3-18 years	19 parents	Explore the experience of hope for families & identify the facilitative circumstances.	Case studies - face to face & internet interviews	Constant comparative method of coding & categorisation (Glaser & Strauss)	Parenting a child with a developmental disability was strengthening experience. Hope strengthened by internal & external resources.	Need to consider how to increase positive & hopeful interactions with parents.
Corman (2009)	Canadian mothers of children (8-18 years) with autism.	9 mothers	Explore positive care-giving experiences of mothers of children with autism.	In depth, semi-structured interviews	Analysed using a modified approach by Moustakas (1994)	Positive experiences gave families hope. Personal transformations reported by all mothers.	Drawing attention to positive experiences to help meaning-making. Positive growth useful intervention

							indicator.
Lloyd & Hastings (2009)	Parents of school aged children with Intellectual Disabilities (ID) aged 3-18years	138 mothers & 58 fathers	Explore hope & its relationship with psychological well-being.	Parent-report questionnaires: The Reiss Scales for Children's Dual Diagnosis, The Trait Hope Scale, Positive Affect Scale of the Positive & Negative Affect Schedule, The Parent & Family Problems Scale of the Questionnaire on Resources, Stress Friedrich Short Form, & The Hospital Anxiety & Depression Scale.	Pearson's correlations & linear regressions	"Hope agency" a resilience factor for psychological well-being. "Hope pathways" a resilience factor for maternal depression.	Increase hope to enable ability to respond to challenges.
Resilience							
Bayat (2007)	Parents & other biological primary caregivers of children (2-18 years) with autism	167 parents	Examine family resilience in families of children with autism.	Survey – three open ended questions	Thematic categorisation	Several resilience/growth processes identified.	Directs service provision towards interventions building strengths.
Reframing Coping Strategies							
Hastings, Allen, McDermott & Still (2002)	Mothers of children with learning disabilities aged 4-19 years	39 biological mothers, two foster mothers	Explore factors related to positive perceptions & experiences.	Parent-report questionnaires, including components of the Family Support Scale (FSS), the Family Crisis Oriented	Regression analyses	Perceptions of child as source of growth & maturity associated with reframing coping strategies, helpfulness & usefulness of support from family &	Positive perceptions an intervention goal in parental work.

				Personal Evaluation Scales (F-COPES) & the Kansas Inventory of Positive Perceptions (KIPP).		friends, & care-giving demand.	
Hastings & Taunt (2002)	Families of children with developmental disabilities	Studies that directly addressed families' positive perceptions or included a variety of positive measures.	Review existing published research on the positive perceptions & experiences of family members.	Review method unclear.	Separated papers into qualitative & quantitative studies.	Range of positive perceptions & experiences reported.	Clinicians need the tools & skills to measure positive growth.
Social Support							
Greer, Grey & McClean (2006)	Mothers of children (aged 5-8 years) with ID	36 mothers	Explore relationship between parental coping strategies & levels of positive perceptions.	Questionnaire parent-report measures: Developmental Behaviour Checklist-Parent Version, Care Demand Scale, Family Support Scale, Family Crisis Oriented Personal Evaluation Scales, F-COPES & Kansas Inventory of Parental Perceptions KIPP.	Hierarchical regressions	Child a source of happiness, strength & family closeness & personal growth & maturity. Helpfulness of formal social support predicted mobilising the family to seek help, which predicted family strength & closeness.	Need to support parents at different stages of the growth process. Positive growth as useful intervention indicator Positive outlook to promote strengths-based approach.

Appendix C

International Classification of Diseases – 10

Autism Diagnostic Criteria

International Statistical Classification of Diseases and Related Health Problems 10th Revision (Childhood Autism, Atypical Autism & Asperger's Syndrome)

Childhood autism

A type of pervasive developmental disorder that is defined by: (a) the presence of abnormal or impaired development that is manifest before the age of three years, and (b) the characteristic type of abnormal functioning in all the three areas of psychopathology: reciprocal social interaction, communication, and restricted, stereotyped, repetitive behaviour. In addition to these specific diagnostic features, a range of other nonspecific problems are common, such as phobias, sleeping and eating disturbances, temper tantrums, and (self-directed) aggression.

Atypical autism

A type of pervasive developmental disorder that differs from childhood autism either in age of onset or in failing to fulfil all three sets of diagnostic criteria. This subcategory should be used when there is abnormal and impaired development that is present only after age three years, and a lack of sufficient demonstrable abnormalities in one or two of the three areas of psychopathology required for the diagnosis of autism (namely, reciprocal social interactions, communication, and restricted, stereotyped, repetitive behaviour) in spite of characteristic abnormalities in the other area(s). Atypical autism arises most often in profoundly retarded individuals and in individuals with a severe specific developmental disorder of receptive language.

Asperger's syndrome

A disorder of uncertain nosological validity, characterized by the same type of qualitative abnormalities of reciprocal social interaction that typify autism, together with a restricted, stereotyped, repetitive repertoire of interests and activities. It differs from autism primarily in the fact that there is no general delay or retardation in language or in cognitive development. This disorder is often associated with marked clumsiness. There is a strong tendency for the abnormalities to persist into adolescence and adult life. Psychotic episodes occasionally occur in early adult life.

(Accessed from World Health Organisation website http://apps.who.int/classifications/apps/icd/icd10online/ on 16.03.2011, 18.35).

Appendix D

Letters of ethical approval for the study

Coventry University
Priory Street
Coventry CV1 5FB
Telephone 024 7688 7688

Professor Ian M Marshall
Pro-Vice-Chancellor (Research)

Coventry University

TO WHOM IT MAY CONCERN

RRU/Ethics/Sponsorlet

24 March 2010

Dear Sir/Madam

Researcher's name: Ms Helen Peckett
Project Title: Exploring the impact of an innovative social skills intervention for children on the autism spectrum on their family relationships

The above named student has successfully completed the Coventry University Ethical Approval process for her project to proceed.

I should like to confirm that Coventry University is happy to act as the sole sponsor for this student and attach details of our Public Liability Insurance documentation.

With kind regards

Yours faithfully

Professor Ian Marshall
Pro-Vice-Chancellor, Research

Enc

Pro-Vice-Chancellor's Office
Direct Line 024 7679 5293
Fax 024 7688 8030

www.coventry.ac.uk

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2007

NHS
National Research Ethics Service
The Black Country Research Ethics Committee
Osprey House
Albert Street
Redditch
Worcestershire
B97 4DE

Telephone: 01527 587573
Facsimile: 01527 587503

11 June 2010

Miss Helen Peckett
20 Stonehouse Close
Cubbington
Leamington Spa
CV32 7LP

Dear Miss Peckett

Study Title: **What is the impact of Lego Therapy, an innovative social skills intervention, on the family relationships of children who are on the autism spectrum?**

REC reference number: **10/H1202/33**
Protocol number:

Thank you for your letter of 28 May 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research

governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. *Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
REC application		25 March 2010
Protocol	2	25 March 2010
Investigator CV		25 March 2010
Participant Information Sheet: Child	1	11 February 2010
Participant Consent Form	1	11 February 2010
Participant Consent Form: Assent Form for child	1	11 February 2010
Evidence of insurance or indemnity	QBE	
Questionnaire: Demographic Information Questionnaire	1	11 February 2010
Evidence of insurance or indemnity	AOW	01 August 2009
Letter from Sponsor		24 March 2010
Referee/Review of Protocol		05 November 2009
Stage One Interview Schedule	1	11 February 2010
Stage Two Interview Schedule	1	11 February 2010
Children's Evaluation Form	1	11 February 2010
Supervisor's CV		
Participant Information Sheet	2	28 May 2010
Response to Request for Further Information		28 May 2010

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H1202/33	**Please quote this number on all correspondence**

Yours sincerely

Anne McCullough [Mrs] *on behalf of*
Dr Jeff Nellson
Chair

Email: anne.mccullough@westmidlands.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Dr. Fiona MacCallum*

Coventry and Warwickshire NHS
Partnership Trust

West Midlands (South) Comprehensive Local Research Network
Fourth Floor, West Wing (ACF40002)
University Hospitals Coventry & Warwickshire NHS Trust
University Hospital
Clifford Bridge Road
Coventry
CV2 2DX

22nd June 2010

Miss Helen Peckett
20 Stonehouse Close
Cubbington
Leamington Spa
CV 32 7LP

Dear Miss Peckett

Project Title: What is the impact of Lego Therapy, an innovative social skills intervention, on the family relationships of children who are on the autism spectrum?

R&D Ref: **PAR300310**
REC Ref: **10/H1202/33**

I am pleased to inform you that the R&D review of the above project is complete, and the project has been formally approved to be undertaken at Coventry and Warwickshire Partnership Trust. Your research activity is now covered by NHS indemnity as set out in HSG (96) 48, and your trial has been entered onto the Trust's database.

The following documents were reviewed:

- **Protocol** Version 2, 25th March 2010
- **Patient Information Sheet Adult** Version 2, 28th May 2010
- **Patient Information Sheet Child** Version 1, 11th February 2010
- **Consent Form Adult** Version 1, 11th February 2010
- **Consent Form Child** Version 1, 11th February 2010
- **Stage 1 and 2 Interview Schedules** Version 1, 11th February 2010
- **Children's Evaluation Form** Version 1, 11th February 2010
- **Questionnaire** Version 1, 11th February 2010 .
- **R&D Application Form** Lock code 42983/109660/14/687 with signed declarations
- **NRES Site Specific Information Form** Lock code 42983/109667/6/711/44169/172021
- **NRES Approval Letter** Dated 11th June 2010
- **Confirmation of Sponsorship** Letter dated 24th March 2010
- **Insurance Policies** Dated 1st August 2009
- **CVs for the Research Team** Signed and dated

Your responsibilities are set out in the attached agreement, which must be signed and returned to the R&D Office. You should keep a copy for your records.

All research must be managed in accordance with the requirements of the Department of Health's Research Governance Framework (RGF) and to ICH-GCP standards. In order to ensure that research is carried out to these standards, the Trust employs the services of an external monitoring organisation to provide assurance. Your study may be randomly selected for audit at any time, and you must co-operate with the auditors.

The duration of Trust approval extends to the date specified in the R&D application form. Action may be taken to suspend Trust approval if the research is not run in accordance with RGF or ICH-GCP standards, or following recommendations from the auditors. Research must commence within two years of the REC approval date and within six months of NHS Permission.

I wish you well with your project. Please do not hesitate to contact me should you need any guidance or assistance.

Yours sincerely

Katie Williams

Katie Williams
Assistant RM&G Project Manager

Enc: CI Agreement

Cc: Ms Jacky Knibbs, Consultant Clinical Psychologist, Coventry and Warwickshire NHS Partnership Trust
Professor Ian Marshall, Sponsoring Organisation, Coventry University

Appendix E

Interview schedule

Interview Schedule (Key questions numbered, prompt questions lettered)

Experience of Lego Therapy

1. Can you tell me about your experience of Lego Therapy over the last 6 weeks?
    a. What went well?
        i. Why do you think that was?
    b. What was difficult?
        i. What problems did you encounter?
        ii. How did you resolve these problems?

2. How did your children engage with the Lego Therapy sessions?

Impact of Lego Therapy on Family Relationships

1. How do you feel Lego Therapy has had an impact on your family?

2. In what ways has Lego Therapy affected your relationship with your child on the autism spectrum?

3. Which three words would you now choose to describe your relationship with your child? *(Pause whilst they list words)*

4. Could you tell me why you chose those words? *(Take words one by one and ask for illustration)*

5. In what ways has Lego Therapy affected the sibling relationship between ? and ? *(insert children's names here)*

6. Which three words would you now use to describe the sibling relationship between ? and ? *(insert children's names here)*

7. Could you tell me why you chose those words *(take words one by one and ask for illustration)*

8. Can you tell me a bit more about any impact Lego Therapy has had on your family as a whole?

9. Do you feel that Lego Therapy has impacted on any of the difficulties you originally described in your family relationships *(go through those described in the original interview one by one and note response)?*

10. In what ways do you think that Lego Therapy has strengthened or weakened your family relationships?
    a. Why do you think this is?

11. What aspects of Lego Therapy do you think was particularly helpful or unhelpful for you and your family?

12. Will you continue to use Lego Therapy sessions within your family, and for what reason?

Impact of Lego Therapy on the child on the autism spectrum

1. How do you feel Lego Therapy has impacted on your child (on the autism spectrum)?

2. Have you noticed any changes in your child since starting Lego Therapy with them? For example:
    a. In their behaviour?
    b. In their communication skills?
    c. In their social skills?

3. What do you think your children thought or felt about the Lego Therapy sessions?

Appendix F

Interpretative Phenomenological Analysis (IPA)

procedure and justification for use

Interpretative Phenomenological Analysis Procedure and Justification

Interpretative Phenomenological Analysis (IPA) can be used to closely examine the experiences and meaning making of participants, and has often been used to explore events of personal significance, such as the development of important relationships (Smith, Flowers & Larkin, 2009). It is also useful when investigating new areas in which theories and research is not well established (Smith et al., 2009). Given both the exploratory nature of this study and the personal salience of family relationships, as well as the lack of research investigating experiences of Lego Therapy, IPA was considered a valid methodology to use within this research.

IPA allows for and takes into consideration the impact of views and expectations of both the researcher and the participants in its analysis (Smith et al., 2009); this fits particularly well with the current study given the inherent involvement of the researcher and the child's parents in facilitating the project and the sessions. Indeed, observer and experimenter bias identified in previous Lego Therapy studies was not accounted for within the quantitative designs employed.

Stages of IPA analysis undertaken (taken from Smith et al., 2009):

- Transcription – Each interview was transcribed verbatim by the researcher from a digital Dictaphone to a Microsoft Word Document. Names and any other identifying information were removed.
- Reading and re-reading – The researcher actively engaged with the data, to ensure the participant becomes the focus of analysis.
- Initial noting – The researcher examined the data for semantic content and language use, noting anything of interest at a very

exploratory level. This included comments at descriptive, linguistic and conceptual levels.

- Developing emergent themes – The researcher mapped the interrelationships, connections and patterns between the initial notes.
- Searching for connections across emergent themes – The researcher then developed a pattern of how the emergent themes fit together.
- Moving to the multiple cases – The above steps were then repeated for each transcript.
- Looking for patterns across cases – Themes across and idiosyncrasies between cases were sought.

Appendix G

Parental participant information sheet

Lego Therapy and the family relationships of children who are on the autism spectrum

I would like to invite you to take part in my research study, undertaken as part of my Doctorate in Clinical Psychology at the Universities of Coventry and Warwick.

What is the purpose of the study?

Lego Therapy is a new therapy for children on the autism spectrum. Lego Therapy involves children working together to build Lego models in small groups. Research has shown it can be helpful in improving children's social skills and challenging behaviours. So far, Lego Therapy has only been tried in groups of children who are roughly the same age and not related to each other. The purpose of this study is to examine what the experience of Lego Therapy is within families and specifically the experience of this in the context of family relationships.

Do I have to take part?

It is up to you whether or not you participate, and your decision will not affect any current or subsequent care you are offered. If you agree to take part, I will ask you to sign a consent form on behalf of both yourself and your participating children. You are free to withdraw from the study at any time, without giving a reason and without this affecting any care you are receiving.

What will my children and I be asked to do if we take part?

1. Lego Therapy Training Session (1 ½ - 2 hours) - An introductory/practice session for your family and others at Orchard House or Stratford Health Care. This will provide you with the chance to learn more about how Lego Therapy works and be able to practice and ask questions.
2. Lego Therapy Sessions at Home (1 hour each session, once a week) – You will be asked to carry out 6 Family Lego Therapy sessions yourselves at home. You may be able to borrow the Lego set(s) required during the study if you do not own your own Lego sets.
3. Interview with parents (approx. 1 hour) –this interview is to find out about your experiences of Lego Therapy

What are the possible disadvantages of taking part?

Time

It would be useful to choose a regular time slot for your Lego Therapy sessions which is easiest for you and your family, and interviews will be arranged at a time and location which is most convenient to you.

Distress

The interviews will require you to think about sensitive issues relating to the quality of your family relationships. It is possible that this

could be distressing to you. Should you require further support following your participation, you will be able to contact any member of the research team who will ensure you are offered appropriate support.

Carrying out a home based intervention might be stressful as a parent. You will be able to contact the research team during the six week intervention block if you need to. In addition, I will telephone you half way through the allotted six week Lego Therapy time frame at a prearranged time to offer support and discuss any difficulties you may be having.

What are the possible benefits of taking part?

Impact of Lego Therapy

The Lego Therapy sessions may have a positive impact on your child's social skills and behaviour, as in previous studies. It may also impact positively on your family relationships.

Opportunity to reflect

The chance for you to talk in depth about your family relationships and your experiences of Lego Therapy may hold some therapeutic value for you. The experience of being listened to and heard may allow you the space to reflect on what works well in your family and where your difficulties lie, which could in turn allow you to think about how to improve your family relationships.

Ethical approval and confidentiality

This study has been approved by The Black Country Research Ethics Committee, Coventry and Warwickshire Partnership Trust Research and Development Team and Coventry University Research Registry Ethics Committee. Both interviews will be audio-recorded. However, all information collected through the study will be treated as confidential and anonymous, and stored securely on NHS premises. It will not be possible to identify you from the completed research. A summary of the results will be sent to you when the study is completed.

Who is supervising the study?

Clinical Supervisor
Ms. Jacky Knibbs
Consultant Clinical Psychologist
South Warwickshire CAMHS
Psychology
Orchard House
83 Radford Road
Leamington Spa
CV31 1JQ
Tel: 01926 881640

Academic Supervisor
Dr. Fiona MacCallum
Associate Professor
Department of
University of Warwick
Coventry
CV4 7AJ

Tel: 02476 523182

Further information and contact details

If you are interested in participating in this study or would like more information, please fill in the expression of interest form below and return it in the pre-paid envelope provided to the following address, by ..... Before doing so, please read the following exclusion criteria for the study, to ensure your family are suitable to participate in this particular study. The following participants are unfortunately not suitable at this stage:

- Children with no siblings.
- Children younger than 5 years old or older than 16 years old.
- Children who do not attend mainstream school.
- Families who are not completely fluent in English language (in order to be able to fully participate in the interview process).

Many thanks and I look forward to hearing from you.

Helen Peckett
Trainee Clinical Psychologist
South Warwickshire Child and Adolescent Mental Health Team
Orchard House
83 Radford Road
Leamington Spa
CV31 1JQ

Tel: 01926 883640

I am interested in finding out more information about the Lego Therapy and Family Relationships study outlined on the information sheet above.

I am happy to be contacted by Helen Peckett (Trainee Clinical Psychologist) using the following details:

Name.....
.....

Home Telephone Number
.....
.....

Mobile Telephone Number
.....
.....

Home
Address.....
.....

.....
.....
In the first instance, you will be contacted by telephone to easily facilitate an open discussion of any questions you have.

Appendix H

Parental participant consent form and demographic information questionnaire

Coventry and Warwickshire NHS
Partnership Trust

Patient Identification Number:

CONSENT FORM

Title of Project: Lego Therapy and the family relationships of children who are on the autism spectrum

Name of Researcher: Helen Peckett (Trainee Clinical Psychologist)

Instructions

Please read the following points and initial each box to indicate that you agree, and please sign and date at the bottom of the form.

- I confirm that I have read and understand the information sheet dated 11th February (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

- I understand that my participation is voluntary, and that I am free to withdraw from the study at any time without giving any reason, without my care or legal rights being affected. ☐

- I understand that by signing this form, I am also providing consent on behalf of my children to participate in the family Lego Therapy sessions, as outlined in the information sheet provided. ☐

- I understand that I can contact Helen Peckett or the supervisor Ms. Jacky Knibbs at any time should I require any further information. ☐

- I understand that any information I provide will be treated as confidential and anonymous. I will not be identifiable from any research findings that are published. ☐

- I agree to take part in the above study ☐

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Name of researcher	Date	Signature

When completed, 1 copy for participant, 1 for researcher.

Demographic Information Questionnaire

About you, the parent:

1. Are you:
    a. the mother
    b. the father

2. How old are you?
    a. Under 20
    b. 20-30
    c. 30-40
    d. 40-50
    e. 50-60
    f. 60-70
    g. 70+

3. What is your working status?
    a. Not currently working
    b. Working part-time
    c. Working full-time

4. What is your marital status?
    a. Single
    b. Separated
    c. Divorced
    d. Co-habiting
    e. In a civil partnership
    f. Widowed

5. How would you describe your ethnic origin?
    White:
    a. White British
    b. White Irish
    c. White Any Other Background (please specify)

Mixed or Mixed British:

d. White and Black Caribbean
e. White and Black African
f. White and Asian
g. Any Other Mixed Background

Asian or Asian British:

h. Indian
i. Pakistani
j. Bangladeshi
k. Any Other Asian Background

Black or Black British:

l. Caribbean
m. African
n. Any Other Black Background

Chinese, Chinese British or Other Ethnic Group:

o. Chinese
p. Any Other Ethnic Group

<u>About your child who has an autistic spectrum disorder</u>

1. Is your child:
   a. Male
   b. Female

2. How old are they? Please write their age in years and months.

---------- years
---------- months

3. How would you describe their ethnic origin?

White:

a. White British
b. White Irish
c. White Any Other Background (please specify)

Mixed or Mixed British:

d. White and Black Caribbean

e. White and Black African
f. White and Asian
g. Any Other Mixed Background

Asian or Asian British:

h. Indian
i. Pakistani
j. Bangladeshi
k. Any Other Asian Background

Black or Black British:

l. Caribbean
m. African
n. Any Other Black Background

Chinese, Chinese British or Other Ethnic Group:

o. Chinese
p. Any Other Ethnic Group

4. What is the reason your child was referred to the CAMHS team?

---

5. What treatment or care is your child currently receiving?
   a. Psychology or Psychotherapy service
   b. Occupational Therapy
   c. Community Nursing
   d. Social Worker input
   e. Psychiatry
   f. Art Therapy
   g. Family Therapy
   h. Other, please state:---

6. Is your child currently taking any medication? If yes, please list here:
    a. Yes
    b. No

<u>About your other child, the sibling who will be participating in the study</u>

1. Is this child:
    a. Male
    b. Female

2. How old are they? Please write their age in years and months.

---years
---months

3. How would you describe their ethnic origin?

White:

    a. White British
    b. White Irish
    c. White Any Other Background (please specify)

Mixed or Mixed British:

    d. White and Black Caribbean
    e. White and Black African
    f. White and Asian
    g. Any Other Mixed Background

Asian or Asian British:

    h. Indian
    i. Pakistani
    j. Bangladeshi

k. Any Other Asian Background

Black or Black British:

l. Caribbean

m. African

n. Any Other Black Background

Chinese, Chinese British or Other Ethnic Group:

o. Chinese

p. Any Other Ethnic Group

4. Does this child have an ASD diagnosis? If yes, please give details:
   a. Yes
   b. No

---

5. Is this child receiving any input from the CAMHS team or extra support at school? If yes, please briefly describe the reason for this.
   a. Yes
   b. No

<u>About any other children you have:</u>

1. How many additional children do you have, on top of the two who will be participating in the study?
   a. 0
   b. 1
   c. 2
   d. 3
   e. 4
   f. 5

g. 6+

2. How old are these children? Please list each of their ages separately.

---

3. What gender are these children? Please write how many additional children you have who are female and how many who are male:
    a. Female =
    b. Male =

Appendix I

Child participant information sheet and child assent form

Lego Club in your Family

What is research? Why is this project being done?

Research is a way we try to find out answers to questions. We want to see if Lego Clubs help people get along better with each other.

Why have I been asked to take part?

You have been asked to take part because you are between 5-14 years old. Children between 5-14 years old have found Lego Clubs most useful in the past. You have also been asked because you have at least one brother or sister, so that you can be part of a Lego Club in your family.

Do I have to take part?

It is completely up to you whether you decide to take part.

What will happen to me if I take part in the research?

1. You will be invited to a Lego Club Meeting with your brother or sister and one of your parents. This will help you to learn more about Lego Club.
2. Next, you will be asked to take part in 6 Lego Club meetings at home with your parent and brother or sister. These will last one hour each and happen once a week. In the Lego Club you will be asked to work together to build Lego Set Models. You will each take it in turns to have different jobs to make sure the model gets built.

Will Lego Club upset me?

You might sometimes find it hard to work together building a model, and following the rules set by the Club. To help with this, your parent will make sure there is a quiet place you can go to during the Club if you need some time out.

Will the Lego Club help me?
We hope that the Lego Club might help you to get along better with others, especially your family. However, we cannot promise that the study will help you but the information we get might help other young people like you in the future.

What if something goes wrong?
It's not at all likely that things will go wrong. If something happens during Lego Club that you are unhappy with, you can talk to either your parents or me about it. If you are still unhappy then your parents will be able to complain for you. If you are upset by the Lego Club, we will make sure you get the right support to help you with this.

What if I don't want to be in Lego Club anymore?
If at anytime you don't want to be in Lego Club anymore, just tell your parents or me. We will not be cross with you.

What's good about Lego Clubs?
Lots of children have been in Lego Clubs with other children and have found them great fun. We hope you'll have fun too!

Thank-you for being part of Lego Club!

Helen Peckett
Trainee Clinical Psychologist

Version 1. 11.02.2010

Coventry and Warwickshire NHS
Partnership Trust

Lego Club and family relationships

Please circle all the sentences you agree with:

Has somebody explained Lego Club to you? Yes/No

Do you understand what Lego Club is about? Yes/No

Have you asked all the questions you want? Yes/No

Have you had your questions answered in a way you understand?

Yes/No

Do you understand that it's OK to stop taking part at any time? Yes/No

If ANY answers are "no" or you don't want to take part, don't sign your name!

If you DO want to take part, you can write your name below.

Your name:_____

Date:_____

The person who explained about the club needs to sign too:

Print name:_____

Sign:_____

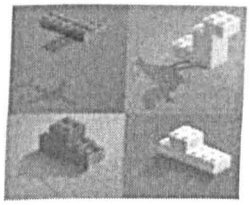
Date:_____

Thank-you for your help!

Version 1. 11.02.2010

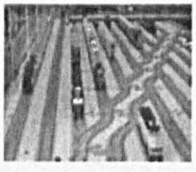
Appendix J

Lego Therapy roles and rules sheets



LEGO® CLUB RULES

1. Build things together!
2. If you break it you have to fix it or ask for help to fix it.
3. If someone *else is using it*, don't take it, ask first.
3. No yelling or screaming.
4. Keep hands and feet to yourself.
5. Use polite words.
6. Each person has a set amount of time to build.
7. Clean up and put things back where they came from.
8. All Lego is to stay in the room.
9. Do not put Lego bricks in your mouth.



Builder

Congratulations - you are now the builder.

The main jobs of the builder are to:

1. Ask the Lego planner how they want you to build the blocks.

2. Listen to what the Lego planner/inventor wants you to build.

3. Build the blocks.

4. If you don't understand what you have to do ask the Lego planner.

LEGO Planner

Congratulations - you are now the planner.

The main jobs of the planner are to:

1. Read the instructions and work out what has to be done.

2. Tell the Lego builder what they are going to build.

3. Help the Lego builder if they get stuck.

4. Help the Lego searcher if they don't know what blocks to find.

Searcher

Congratulations - you are now the searcher.

The main jobs of the searcher are to:

1. Find the right blocks to build the model.

2. Give the right blocks to the Lego builder.

3. Ask the Lego planner for help if you can't find the right blocks.

Appendix K

Example section of a *coded transcript*

Children loved Lego.

Umm...I think they loved it. I mean they really have honestly loved it. It's been, it's been a joy to do, and they've been so like "is it Friday yet, can we do our session?!"

Aaah

No it's Thursday. Can't we do it early? No, we're doing that tomorrow morning. Oh, okay. And as soon as we've had breakfast, it's the fastest breakfast of the week for Chris. I mean he can take an hour, hour and a half to eat his cereal

~~Engagement~~

Excitement ↑ motivation for less favoured activities — impact widened beyond Lego.

Yeah

Umm but on Friday, it was eaten in about 10 minutes and he was off getting dressed and then he'd come down and do the Lego, so it's been really nice to have a reward at the end of the week that they've both really enjoyed.

Yeah, good timing actually.

Yeah

Okay, good. Umm...and how do you think that Lego Therapy has impacted on your family in general?

Whole family impact.

Umm, I think all round it's been really nice because although it's only been myself and the two boys, their Dad hasn't done any sessions with them, I think it's had a positive effect on all our relationships and it's certainly enabled me to sort of say to my husband, look Danny has problems with verbal language, if you speak to him quickly, you might as

Shared learning ↓ other family members → extended impact

Kids really really loved it

A joy

Excited each Friday/ session

Excited to do Lego.

Helped other daily activities because excited to do Lego

Reward for children really enjoyed.

Really nice for family.

+ve impact on all rel's.

Helped to share difficulties + be able to explain to husband - he helped other family members' rel's ↓ children too.

well just not bother because he won't follow all that you're saying, and that's helped him understand that it's not just him

Hmm mmm

Because Graham tends to sometimes see Danny and him, himself, being in some sort of long-lasting battle, whereas now I think he can see that it's actually genuinely a problem for Danny, and it has helped him to speak slower and calmer with him, just because I can say, look, it's not you, it is just he can't cope with that speed

Yeah

So it's helped with that. It's certainly helped Danny and Chris, they're squabbling less. It sounds pathetic, they're children, they squabble

Yeah

But it's made them both realise that they have to speak nicely to each other, if they want to get somebody to do something, yelling at the top of your voice is probably not the best way to go about it

Yeah

And you have to be calm, and talk to each other and help each other, which has been nice. And I think for me, it has given me some time to see the boys as individuals, and to do something they really enjoy with them, which is nice.

Pos. impact on extended fam. rel's.

Helped improve comm. skills.

Helped sibling rel - less squabbling.

Better comm. — learnt through Lego.

Calmer rel / Comm.

Ind. diff's.

Shared time

Helped Dad understand son's difficulties.

Can see father-son rel as battle. Helped see as genuine prob + communicate better.

certainly helped DTC rel - less squabbling.

↳ dev. stage - appropriate.

kids learnt how to speak nicely to others, better comm.

Calm / helpful comm nice.

Nice for Mum to see kids as individuals + share enjoyed time + them.

Great, good. Umm, and in particular in the last interview I know we talked more about Chris.

Yeah

So is there anything that you feel, or any ways that you think Lego has affected your relationship with him in particular?

I think in some way, I thought about this and I can't really explain why, but Chris has PDA and the symptoms of that are a lot, lot less.

Oh right

We've had far fewer flinging himself around, slamming doors, I mean we've had the odd blow-up but nothing as bad as it can be

Okay

And I wonder whether that's because we're speaking more clearly, maybe we're speaking slower, and I think it just, in some weird way, and I can't quite put my finger on it, it has definitely reduced that

Okay, brilliant

And I think that my relationship with Chris is better in that umm, I think he's, he's a lot more receptive when I'm asking him to do something that he doesn't particularly want to do. He had his birthday, was it about 10, two weeks ago now

Okay

Difficult to articulate reasons behind change.

Less PDA symptomology.

Impact of better comm.

Lego helped reduced PDA symptomology

Process unclear.

Better mother-son rel.

Things changed & © in difficult to articulate why PDA symptoms much less

Poss due to clearer/slower communication

Lego helped PDA in weird/hard to explain why - not easy to see how it works.

Better mother - son rel - more receptive to demands

And he has to do thank-you letters for people that weren't there. And he's done them and written them in half an hour! And I think he's just accepting that there are things that we like doing and things that we don't like doing. But because I'm probably speaking more clearly, more calmly, umm, he's far more willing to do things that he doesn't particularly like doing

Okay

And he's coping when things go wrong a bit better, which has been nice. Umm, we had uhh, an incident last week when I got a speeding ticket, or rather I went through a speed camera and it flashed, but he noticed

Yeah

First time in 16 years I hasten to add, but he was inconsolable, for the day, just an absolute panic-stricken about what was going to happen and why, and in the evening he was in tears again at bedtime and I said, right we're going to throw that worry in the bin, and he sort of looked at me, and normally he'd just brush it away, no I'm not doing that, it's silly. But I managed to get him to think about what this worry looked like, opened his bin and he threw it in. And I said to him, right it's staying there and tomorrow morning we'll flush it down the loo and it's gone. And we did, and it worked brilliantly, he stopped worrying about it

Okay

But he was so much more receptive to the idea, I've tried it before on him, and it's like well I can't take a worry out of my head, but he could

Impact of clearer comm learnt in Lego on PDA.

More receptive to abstract ideas

↑ ability to think abstractly.

© more accepting that always things don't like but have to do.

Clearer, calmer comm (as a result of Lego) – more willing

Coping better

When things go wrong → panic / tears.

More receptive to Mum's strategies to help him cope

more receptive to idea

more able to think abstractly

Practiced abstract thought in Lego - helpful.

actually understand that idea and I think that's because we've been talking about things like putting the Lego bricks onto the model, which is explaining a concrete idea abstractly

Due to talking abstractly in Lego

Yeah yeah

Does that make sense? And I think he's just got the idea that you can talk about something even though it's not you doing it, do you know what I mean, does that make sense?

Trying to articulate Better at abstract thinking

Yeah

Abstract thinking helped w emotions.

He's kind of got that abstract concept a bit more which has been a big help with those strong emotions that he gets.

↑ in abstract thinking helping w his strong emotions.

Okay, good.

It's been nice.

Nice

Yeah, that sounds great. So, I know you described your relationship with Chris positively before

Yeah

Loving Respectful calm rel.

And there was the question about the three words, if you were going to pick three words now to describe your relationship, what would you pick?

Umm, I think we'd have loving, respectful and calm.

Loving, respectful, calm rel.